Therapy and equipment needs of people with cerebral palsy and like disabilities in Australia

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Therapy and equipment needs of people with cerebral palsy and like disabilities in Australia

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Contents

Abbreviations

ABI	Acquired brain injury
ABS	Australian Bureau of Statistics
ACT	Australian Capital Territory
ADL	activities of daily living
AFO	ankle foot orthoses
AIHW	Australian Institute of Health and Welfare
AIL	activities of independent living
AWEC	activities of work, education and community living
COPM	Canadian Occupational Performance Measure
CP Australia	Cerebral Palsy Australia
CPAWA	Cerebral Palsy Association of Western Australia
CPLQ	Cerebral Palsy League of Queensland
CSTDA	Commonwealth–State/Territory Disability Agreement
FIM	Functional Independence Measure
FTE	full-time equivalent
GMFM	Gross Motor Function Measure
ICF	International Classification of Functioning, Disability and Health
GAS	Goal Attainment Scaling
GMFCS	Gross Motor Function Classification System
HACC	Home and Community Care
n.a.	not available
n.e.c.	not elsewhere classified
NDA	National Disability Administrators
NMDS	national minimum data set
NSW	New South Wales
NT	Northern Territory
OH & S	occupational health and safety
PADP	Program of Appliances for Disabled People
PEDI	Pediatric Evaluation of Disability Inventory

Qld	Queensland
RAP	Rehabilitation Appliances Program
SA	South Australia
SDAC	Australian Bureau of Statistics Survey of Disability, Ageing and Carers
Tas	Tasmania
Vic	Victoria
WA	Western Australia

Symbols

. .	not applicable
—	zero, or null cells
0.0	rounded to zero (less than 0.5 but more than zero)

Summary

This report considers the need for therapy and equipment among people with cerebral palsy and related conditions. The project was undertaken jointly by the Australian Institute of Health and Welfare (AIHW) and Cerebral Palsy Australia (CP Australia). Both organisations contributed 'in kind' resources to the project, and were supported by funding from the Telstra Foundation. The AIHW was responsible for the project methodology, analysis and reporting. CP Australia provided advice to the AIHW team and contributed a depth of professional knowledge regarding cerebral palsy and like disabilities and the experiences of CP Australia clients, families and professionals.

Objectives

There were three key objectives:

- To review and summarise the key findings of national and international literature about the definitions, costs and benefits of therapy, and whether therapy 'makes a difference' for people with disabilities related to, or similar to those related to, cerebral palsy. That is, the relationship of therapy to improvements in, and maintenance of, levels of functioning.
- To identify the nature and quantify the extent of met, partially met and unmet need for therapies and equipment among people, of different ages, with cerebral palsy and similar disabilities.
- To estimate the effects of the provision of therapy and equipment in terms of improved or maintained individual functioning and participation, at different ages, and in terms of reduced social costs of disability.

Main information and data sources

The AIHW sought all relevant information on met and unmet need for therapy and equipment among people with CP and like disabilities. In addition to an extensive review of literature, this included bringing together information from four key data sources:

- the ABS Survey of Disability, Ageing and Carers (SDAC) (Chapters 4 and 7)
- the Commonwealth–State/Territory Disability Agreement National Minimum Data set (CSTDA NMDS) (Chapter 6)
- information from CP Australia agency records (Chapter 6)
- archetypal cases, providing detailed hypothetical profiles of typical clients and the type, quantity, and cost of therapy and equipment they require to meet their needs (Chapter 8).

Focus groups involving people with cerebral palsy and their families, as well as therapists in the field, provided a rich information source to complement the data. In all, 12 focus groups were held in four Australian states: New South Wales, Victoria, Queensland and Western

Australia. A total of 52 clients (adults, and families of children with cerebral palsy and like disabilities) and 65 professionals were involved (Chapter 5).

People with CP and like disabilities in Australia

*(*Chapters 4, 6 and 7*)*

The combined population estimate of CP and CP-like disabilities is 33,800 people in 2003, which includes 16,100 people with a disability associated with CP and 21,200 people with CP-like disabilities who may need therapy and equipment services. Some people have both CP and CP-like disabilities.

The inclusion of people with CP-like disabilities in the project was important. Comparative analysis showed that the CP-like population group had similar support needs and reasonably similar disability patterns to those of the CP population group and CP Australia agency service users.

Throughout the study, need for assistance with core activities (self-care, mobility and communication) was used as an indicator of disability severity and potential need for therapy and equipment. Compared with the broader population with disability, people with CP and CP-like disabilities were more likely to need very frequent assistance with core activities (6 times a day or more), and had higher rates of need for assistance with self-care and communication. This was largely due to the criterion used to identify this group in the population data, restricting it to persons needing frequent assistance (at least daily) with one or more core activities. Of the 33,800 people with CP and like disabilities, 2,000 people lived in cared accommodation. Of those living in households, 26,500 people needed assistance with core activities.

During 2003–04, 9,398 people used services provided by CP Australia agencies (plus one related agency) under the CSTDA. Compared with all other CSTDA service users, CP agency service users were younger, had more complex disabilities, and had higher support needs.

Therapy and equipment—do they make a difference?

*(*Chapters 3 and 5*)*

Therapy encompasses a wide range of interventions which aim to improve the wellbeing of an individual in society. While additional disciplines can play a role in providing therapy to people with CP and like disabilities, it was agreed that physiotherapy, occupational therapy, speech pathology, psychology, and social work would constitute the core therapies for consideration. Equipment is often used as a component of, or as an enhancement to, therapeutic intervention.

Many of those consulted during this project expressed support for the view that therapy and equipment deliver benefits to people with CP and like disabilities. People with disabilities and their families commonly attribute improved levels of functioning to therapy, and see therapy and equipment as crucial in supporting independence, facilitating participation and contributing to overall wellbeing. Put simply, therapy and equipment are considered real needs by many people with cerebral palsy and similar disabilities. This view emerged clearly from the focus groups, notwithstanding the fact that there is little published research evidence to date to either support or reject the claimed benefits. Establishing efficacy by classic research design appears problematic, but new forms of research are emerging and evidence may appear in time.

The potential for therapy and equipment provision to reduce the social cost of disability was widely supported by people with CP and CP-like disabilities and therapists in the field. Mechanisms for this include reduced demands on carers and family, and reduced demands on other service systems (particularly health services) due to the role of therapy in facilitating improved levels of functioning for people with CP and like disabilities. Also, timely therapy input may help to avoid or minimise problems with functioning that may otherwise arise later in life and require more costly interventions. However, it is not currently possible to quantitatively evaluate the effects of therapy and equipment provision, either in terms of individual participation or reduced social costs.

The nature of unmet need

(Chapters 5, 6, 7 and 8)

The nature of unmet need was explored through several of the quantitative and qualitative information sources outlined above. A picture emerged of a service system with clients and therapists under pressure. Focus group participants—both therapists and people with CP and like disabilities—reported significant levels of unmet need, and this was supported by analysis of the available data sources.

Unmet need appears to be particularly high for types of therapy that support participation, especially in employment and social activities, for direct, hands-on therapy (especially physiotherapy), and for social work, psychology and family support interventions. There are long waiting times for therapy and equipment. Unmet need appears to be more of an issue for people living in non-metropolitan or lower socioeconomic areas, and for adults.

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

The extent of met and unmet needs for therapy and equipment (Chapter 9)

Estimation of the extent of met and unmet need for therapy is based on the use of three data sources:

- national population data—the ABS Survey of Disability, Ageing and Carers
- national disability services data—the CSTDA NMDS
- archetypal cases— hypothetical typical client profiles developed as a vehicle for gathering information from therapists about the therapy and equipment needs of different client groups and the extent to which these needs are met, in order to fill gaps in the national population and disability services data.

Based on combinations of these data sources, three estimates of the annual cost of meeting unmet need for therapy were generated. Each estimate can be interpreted as the additional government funding needed by CSTDA agencies to provide therapy services for clients with CP and like disabilities.

Development of all three estimation methods was guided by the principle that any assumptions employed should, on balance, be conservative so as not to over-estimate the cost of meeting unmet need. Furthermore, it should be noted that none of the three estimates cover possible unmet need for therapy among people with CP and like disabilities not in contact with CP agencies and other similar specialist agencies.

The three separate estimates of the cost of meeting unmet need were produced by using data sources in different pair-wise combinations, to which were applied different assumptions. The data sources were combined in the following pairs:

- Population (SDAC) data together with CSTDA NMDS data for CP Australia agency clients
- Population (SDAC) data together with archetypal cases data
- CSTDA NMDS data for CP Australia agency clients together with archetypal cases data.

Information about need for assistance with core activities (self-care, mobility and communication), available in both the population and disability services data, made it possible to relate all three data sources using different levels of disability severity.

Notwithstanding the use of conservative assumptions, the three different estimate procedures generated diverse estimates of the cost of meeting unmet need, with the highest of the three estimates more than two times the lowest estimate:

• $22.5 million	Population (SDAC) data together with CSTDA NMDS data for CP Australia agency clients
• $32.7 million	Population (SDAC) data together with archetypal cases data
• $54.8 million	CSTDA NMDS data for CP Australia agency clients together with archetypal cases data

None of the three estimates should be regarded as definitive or preferred to the others, and all must be interpreted in light of the data and assumptions that underpin them.

The fragmentation and complexity of equipment schemes, and temporal fluctuation in available funding makes it very difficult to estimate the cost of meeting unmet need for equipment nationally. Equipment waiting list data for three states were used to produce estimates of the annual national cost of meeting unmet need for equipment for people with CP and CP-like disabilities. These estimates range from $3.5 million to $4.4 million.

Acknowledgments

Project team and AIHW support

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Report preparation and over-arching analysis: Ros Madden, Nicola Fortune, Dr Xingyan Wen, Louise O'Rance, Sally Bullock, Dr Samantha Bricknell

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Project officers: Jim Burns, Natalie Georgeff, Glenda Grimley, Dr Leanne Johnston, Sonya Murchland, Iona Novak, Vicki O'Halloran, Matthew Sealy, Erin Wilson

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Disability Policy and Research Working Group

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Project Advisory Committee

Ian Spicer (Chair; AIHW Board representative), Ken Baker (ACROD), Graeme Dargie (consumer representative), Paula Dyke (CP Australia), Dr Maree Dyson (Transport Accident Commission), Anita Ghose (CP Australia), Rosalie Hardy (Disability Policy and Research Group representative), Dr Richard Madden (AIHW), Ros Madden (AIHW), Dr Jane Tracy (Centre for Developmental Disability Health Victoria, Monash University).

Focus groups and archetypal cases therapist groups

The information provided by focus group participants was of great value to the project. The archetypal cases methodology relied on the contributions of teams of allied health professionals in WA, SA, Qld and NSW. The donation of time and the sharing of experience and opinions by these individuals is gratefully acknowledged.

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Expert advice on archetypal cases

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Dr Terry Neeman provided statistical advice on the archetypal cases analyses.

Appendix D was written by Ron Widdison of the Cerebral Palsy Association of Western Australia.

1 Introduction

This chapter outlines the project objectives and provides a profile of the project partners. A brief description of the service context in which the study takes place follows. The chapter concludes with an outline of the methods used and the contents of the report.

1.1 Project objectives and partners

Project objectives

The objectives of the project were to:

1. Review and summarise the key findings of national and international literature about the definitions, costs and benefits of therapy, and whether therapy 'makes a difference' for people with disabilities related to, or similar to, cerebral palsy—that is, the relationship between therapy and improvements in, and maintenance of, levels of functioning.
2. Identify the nature and quantify the extent of met, partially met and unmet need for therapies and equipment among people of different ages with cerebral palsy and similar disabilities.
3. Estimate the effects of the provision of therapy and equipment in terms of improved or maintained individual functioning and participation at different ages and in terms of reduced social costs of disability.

A project partnership

The project was undertaken jointly by Cerebral Palsy Australia (CP Australia) and the Australian Institute of Health and Welfare (AIHW). Both organisations contributed 'in kind' resources to the project, and were supported by funding from the Telstra Foundation.

The project outline and plan were developed in discussions between CP Australia and the AIHW over a period of some two years. Once funding was obtained, the project began with a project initiation workshop held on 15 March 2005. Most of the work took place over the following year, with the investigation finishing in June 2006 and the report being drafted, discussed and finalised between April and September 2006.

Cerebral Palsy Australia

CP Australia is a national non-profit association, which represents the interests of people with cerebral palsy and similar disabilities and their families. Established in 1954, CP Australia (formerly the Australian Cerebral Palsy Association) has provided a national focus for disability awareness, service development for children and adults with cerebral palsy and other disabilities, and related issues reflecting community values such as integration, acceptance and valuing of people with disabilities. It specifically aims to develop strategic alliances with key organisations and individuals; share information among the disability service sector and wider community; and lead service and policy development.

Member organisations of CP Australia comprise the major service providers for people with cerebral palsy and their families in most states of Australia (Table A1.1). These organisations provide a range of services to Australians with cerebral palsy and like disabilities of all ages through more than 600 outlets across the country. In 2004–05, organisations making up CP Australia had a combined budget exceeding $281 million—on average 70% from government funding (Table A1.1). CP Australia estimates that, together, these organisations provide regular services to more than 19,000 people with cerebral palsy and like disabilities:

- over 8,000 aged 0–18 years
- almost 12,000 aged over 18 years, including 1,500 using employment services.

In addition, approximately 15,000 people with cerebral palsy and like disabilities of all ages receive irregular services such as consultation, training and provision of equipment.

Australian Institute of Health and Welfare

The AIHW is a statutory authority of the Australian Government. As Australia's national agency for health and welfare statistics, the AIHW's mission is to inform community discussion and decision-making through national leadership and collaboration in developing and providing health and welfare statistics and information. The AIHW manages many national data collections, and much of its work centres on promoting quality and consistency among national, state and territory statistics, enabling the production of national data to promote discussion and inform decisions on health, housing and community services.

The AIHW welcomed the opportunity to be involved in this important and challenging project. The project demands the production of high quality, robust information that will withstand the scrutiny of the diverse stakeholders in the disability field, and of people in other areas of government with roles in funding decisions. The AIHW's extensive experience in this type of work, and its reputation as an authoritative and independent national statistical organisation, make it well placed to work with CP Australia to produce a report of value to both CP Australia and the wider Australian community.

1.2 The service context: therapy and equipment

This section provides a brief description of the service context under examination in this study.

Therapy

CP Australia agencies are at the core of the study. Services provided by CP Australia agencies chiefly comprise accommodation, respite, day options, school support, community development, employment support, aids and equipment, outreach, therapy and other supports including brokerage, health care, information, research, training, and transport. As stated previously, these agencies receive approximately 70% of their income from government sources. The government funds for these services are administered through the CSTDA.

The CSTDA provides the national framework for the funding and provision of specialist disability services. The major services groups are: accommodation support, community support services, community access services, respite services (all the responsibility of state and territory governments) and employment services (the responsibility of the Australian government). The 'community support' group of services includes therapy, early intervention and case management, all closely related to the theme of this study. Indeed, therapy and therapy-related interventions may sometimes be provided by other CSTDA-funded community support services, not only those designated 'therapy services'. National data on these services and their clients are collated annually by the AIHW in cooperation with all the Australian governments, as specified in their agreed CSTDA National Minimum Data Set (NMDS).

One of the aims of the project is to quantify the extent of unmet need for therapy and equipment among people with cerebral palsy and similar disabilities. Estimates of the cost of meeting this unmet need are presented in Chapter 9 of the report. This component of the project fits into a research gap, in that the AIHW has previously undertaken studies, commissioned by the National Disability Administrators (now called the Disability Policy and Research Working Group), to quantify unmet need for specialist disability services in the CSTDA service groups accommodation support, community access, respite services, and employment services (AIHW 1997, 2002). Community support services were not included in these previous studies.

Health departments and services also provide and fund therapy. For the population under consideration in this study, these services usually take the form of outpatient physiotherapy, occupational therapy, speech pathology and, to a lesser extent, social work and psychology services. These services are generally generic in nature, with adults with cerebral palsy and families of children with cerebral palsy and like disabilities often able to access time limited services related to a particular health issue, for example treatment following a hip replacement, fractured limb or surgical procedures. In more rural and remote areas of Australia, outpatient therapy services provided by the health department are often the only option for people with cerebral palsy and like disabilities and their families wanting to access allied health therapy services.

In addition, people with cerebral palsy and like disabilities may choose to supplement services provided by CP Australia organisations with services from private providers of therapy and psychosocial services.

Equipment

People with cerebral palsy and like disabilities use a variety of aids and equipment to facilitate functioning and participation in all aspects of life. Commonly used items include wheelchairs, standing frames, orthoses, hoists, adjustable beds, shower chairs, continence aids, communication boards and speech synthesisers.

CP Australia organisations around the country provide a range of different services in relation to equipment for people with cerebral palsy and like disabilities and their families. Some organisations provide a specialist equipment service, usually a consultancy service providing advice, support and technical expertise in the assessment, prescription and procurement of functional and positional equipment to clients, families and other therapy staff. The organisations providing a comprehensive equipment service usually have on site a bioengineering workshop for the production and repair of postural and functional equipment. Other organisations provide only an advice and consultancy service regarding equipment, with clients being re-directed to a specialist equipment supplier or the Independent Living Centre in their state for more specialist advice and equipment hire/loan if required. The Independent Living Centre provides ideas and advice on equipment, home modifications and adult therapy services to people with disabilities. The Centre also operates an equipment hire service providing clients with the ability to trial equipment items before purchase, and meet short-term equipment needs. As adults and children with cerebral palsy and like disabilities often have complex communications needs, several of the CP Australia organisations have particular services that are dedicated to providing advice and support to assist individuals to achieve their communications goals for work, learning and recreation (for example the Communication Resource Centre at SCOPE in Victoria).

Therapists play a significant role in the provision of advice, assessment and prescription of equipment. This information is then provided to the supplier of the equipment, who may or may not be part of their organisation: in many cases this is a private supplier who manufactures and produces the equipment.

Each state and territory in Australia has a government-funded aids and equipment program to assist people with disabilities attain subsidised aids, equipment and home modifications to enhance their safety and independence. These schemes are operated differently in each state, with some variation in eligibility criteria, items able to be funded and the extent of subsidy provided. A number of schemes are additionally funded by the Australian government, providing aids and equipment for specific purposes (for example to facilitate participation in employment). However, these can be quite fragmented in nature and clients may need to seek funding from multiple sources (see Table 1.1 for examples of the variation in funding schemes available to people with CP and like disabilities). Further, children and adults with cerebral palsy and like disabilities may require complex pieces of equipment (for example walking aids and communication devices) that may attract limited government funding. Families and individuals then pay for the gap in the price of the equipment, sometimes undertaking fundraising activities to be able to do so.

Table 1.1: Equipment funding schemes: examples of variation

Jurisdiction	Program	Eligibility criteria	Notes
NSW	Program of Appliances for Disabled People (PADP)	• All applicants aged under 16 are eligible • Means test for applicants aged 16 and over • Clients with a single income greater than $26,759 p.a.(a) or couple income greater than $45,490 are only eligible to apply for items costing $800 or more • Ineligible: outpatients, clients with far advanced progressive disease, recipients of community nursing assistance, compensable clients, clients who can claim the cost of the aid from private health insurance, residents of DOCS facilities for people with developmental disabilities, residents in nursing homes and hostels	• $100 co-payment per client per year • Lower income applicants given priority • High income earners (>$39,941(a) p.a. for a single person or >$67,899 p.a. for a couple) are required to pay 20% of the cost of the equipment • Any additional costs for upgrades of the approved item must be met by the client
Vic	Victorian Aids and Equipment Program (A&EP)	• Any client with a long term disability verified by medical practitioner may be eligible • Ineligible: recipients of the supported accommodation equipment access scheme, Department of Veteran Affairs gold card holders, residents of public residential care facilities, inpatients of hospitals, recipients of compensation from Victoria work cover authority, clients able to claim through private health insurance, clients <30 days post-discharge where aid is related to their hospital stay	• Client pays the difference between item cost and subsidy cost
WA	Community Aids and Equipment Program (CAEP)	• Concession card holders eligible (pension, health care, Commonwealth seniors, carers payment) • Others can apply for consideration on the grounds of financial hardship, with eligibility assessed by a social worker • Ineligible: hospital patients immediately post-discharge, residents of public aged care accommodation, eligible for equipment under other programs e.g. Rehabilitation Appliances Program (RAP)	• Applicant owns item if contributed >50%, are consumable or are home modifications • Recyclable equipment remains property of service provider • Maintenance is the responsibility of service provider
Qld	Medical Aids Subsidy Scheme (MASS)	• Concession card holders eligible (pension, Department of Veterans' Affairs, health care card, Queensland seniors card) • Ineligible: Workcover recipients, RAP recipients, some aged care residents, hospital inpatients, palliative care, ostomy association persons, compensation claims, children <5 for incontinence pads or nappies	• MASS retains ownership of loan aid and assumes responsibility for repairs/maintenance

(continued)

Table 1.1 (continued): Equipment funding schemes: examples of variation

State	Program	Eligibility criteria	Notes
SA	Independent Living Equipment Program (ILEP)	• Clients of Options Coordination, who are living in or returning to community accommodation (own home or group home) • Ineligible: compensable clients, people eligible to receive the aid from another funding source (e.g. RAP, CAAS), residents of Commonwealth-funded aged care accommodation	• Equipment items specifically and only for work, recreation or study are not funded • Equipment remains the property of ILEP and must be returned when replaced or no longer used
ACT	ACT Equipment Scheme (ACTES)	• Holders of a concession card (Pensioner, Health Care Card, children under 16 whose parents have a Health Care Card for Carer Allowance in the child's name) with a permanent disability of at least 2 years' duration • Ineligible: persons who are eligible to receive assistance from other government-funded schemes, private health schemes or injury compensation	• Clients contribute 1/3 of the cost of equipment maintenance
Australia-wide	Continence Aids Assistance Scheme (CAAS)	• People aged 16–65, with permanent loss of bladder or bowel function due to a permanent neurological condition or permanent and severe intellectual disability, who are also eligible for the Disability Support Pension or Mobility Allowance • People aged over 65 are eligible if in paid employment for 8 or more hours per week • Ineligible: residents of Commonwealth-funded aged care homes; people eligible for assistance from the Rehabilitation Appliances Scheme or Stoma Appliance Scheme • Incontinence that is treatable by medication or surgery, resulting directly from medication, surgery or diseases such as cancer, stress incontinence and intermittent incontinence are not covered	• Provides a subsidy of up to $470 per year towards continence aids ordered through Intouch • Current clients do not need to reapply each year
	Rehabilitation Appliances Program (RAP)	• Gold Card and White Card holders are eligible (certain Australian veterans, war widows/widowers and dependents) • Ineligible: residents of aged care homes, hospital in-patients	• Operated through the Department of Veterans' Affairs • Provides 'self-help and rehabilitation equipment'
	Workplace Modifications Scheme	• People with a permanent disability lasting, or likely to last, at least 2 years, that restricts everyday work activities and requires a work-related adjustment • Eligible employment must be 8 hours or more per week, for 13 weeks or more • Ineligible: people undertaking work experience, trainee placement, unpaid work or Work for the Dole program participants; recipients of a workers compensation payment against the current employer that covers the modifications being sought	• Funds workplace modifications for people with a disability in employment or seeking employment • Modifications should move with the worker for whom they were purchased when changing jobs

(a) 2005 figures, indexed annually.

1.3 Project components and methods

Project coordination

The project was planned and coordinated by the AIHW, in regular communication with and with guidance from a small steering group of key CP Australia and AIHW people.

The work was carried out by a team comprising AIHW analysts and researchers, and CP Australia staff from all major agencies. Each state and territory CP Australia member agency nominated a liaison person who managed and facilitated CP Australia elements of the work. The AIHW team was responsible for the design, management and conduct of all the main project components as outlined below, as well as for reporting on the project.

A Project Advisory Committee was established, to advise on the methods, key questions and decisions in the course of the project.

An Expert Costing Panel advised on a specialised component of the project (the archetypal cases analysis described below).

All people involved are listed in the Acknowledgments section at the front of this report.

Project components and methods

The key components of the project method were as follows.

A literature review was clearly an essential project component. Many of the key terms and ideas reflected in the project objectives, such as 'therapy', 'efficacy', and 'need', required careful thought and understanding of other work and ideas in the field.

Discussion with people with cerebral palsy, their families, and therapists was also essential, to ensure that the study team understood their perspectives and experiences, and sought information meaningful to them. A total of 12 focus groups were held, at various stages of the project.

Four strands of data analysis were planned and undertaken.

- Analysis of CP Australia client records, costs and waiting lists—this was to enable data to be assembled about the services provided to CP Australia clients, as well as to ensure that information known to CP Australia agencies about unmet need was captured.
- Analysis of data about CSTDA services broadly, and comparisons of CP Australia agencies and their clients with other agencies and clients, enabled the profile of people with CP and like disabilities to be fleshed out, and a picture of their met demand assembled.
- Population data analysis was undertaken, to seek population indicators of need for therapy and equipment among the population with CP and like disabilities.
- Developing and costing 'archetypal cases'—this special methodology was developed to make links between the administrative records and the population data. The purpose was to fill some of the anticipated gaps in the national population and service data.

Where possible, data from more than one source are used to confirm orders of magnitude of estimates.

1.4 Report outline

Following this introductory chapter there is an explanation of the key concepts underlying the project's objectives, the team's approach to them, and the links between these key concepts, the project objectives and the available data—the 'framework and foundations' of the project outlined in Chapter 2. Chapter 3 contains the literature review. These first three chapters provide the contextual material for the information and analyses that follow.

Chapter 5 summarises the discussions of the 12 focus groups and the issues raised by them.

Chapters 4, 6, 7 and 8 present the data analyses. Chapter 4 presents and explains the basic data on the population with cerebral palsy and 'like disabilities'. Chapter 6 presents a statistical picture of the clients and activities of CP Australia agencies, and compares them to other agencies (and clients) receiving CSTDA funding; this analysis builds a picture of 'met demand' and confirms the basic profile of 'CP and like disabilities'. Some information on unmet need from CP Australia agencies is also presented here.

The national data on needs are compiled in Chapter 7, combining further population data with the data from Chapter 6. Focus group material is used to enhance the interpretation of the data.

Chapter 8 explains the 'archetypal cases' methodology and uses the resulting data collected to profile met and unmet needs and to provide estimates of the cost of meeting these needs.

Chapter 9 combines the results from the preceding chapters, to answer and discuss the study's main questions:

- Does therapy make a difference?
- What are the met and unmet needs for therapy and equipment (in terms of both people and costs)?
- What are the effects of therapy and equipment on functioning and participation?

2 Framework and foundations

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

The project objectives contain a number of concepts that are important, but sometimes difficult to define or to measure. This chapter sets out the approach to definition and measurement and indicates broadly how the study team has related these ideas to the available data sources. The following chapters use and expand on these ideas and methods.

2.1 Frameworks, concepts and definitions

Disability, the ICF and the underlying framework for the study

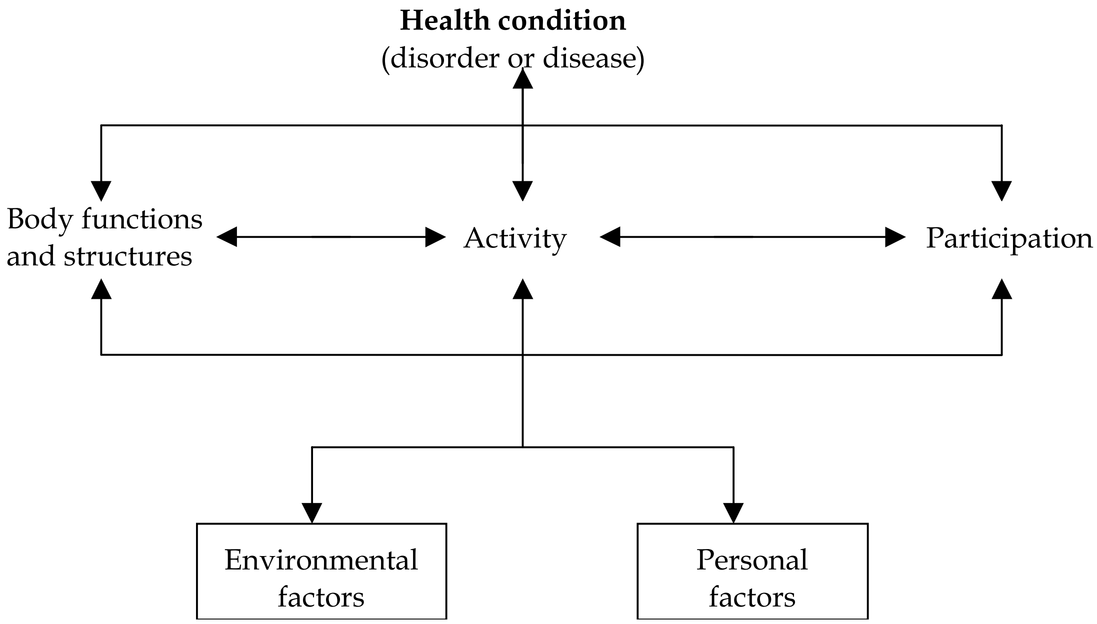
This study focuses on people with disabilities—disabilities related to, or similar to those related to, cerebral palsy. Functioning and disability concepts themselves shape ideas about the need for and outcomes from services and assistance. Recognising these connections, many CP Australia agencies use the broad framework of the International Classification of Functioning, Disability and Health (ICF) (WHO 2001) to unify the key concepts of disability, and to underpin policy development and models of service delivery.

In the ICF, disability is conceptualised as multi-dimensional, relating to the body functions and structures of people, the activities they do, the life areas in which they participate, and factors in their environment which affect these experiences (see Figure 2.1).

The disabilities of people with cerebral palsy can be represented as any or all of: an impairment (for instance an impairment of muscle tone); an activity limitation (for instance a mobility limitation); and a participation restriction (for instance a restriction in employment). Crucially, all of these aspects of disability may be affected by environmental factors (for instance, physical access to buildings or societal attitudes).

Therapy and equipment may be planned and provided with a number of goals in mind—to improve body functioning, to reduce activity limitations, and/or to promote participation. Equipment can be an important part of the immediate environment of a person with a disability.

Setting goals provides a basis on which to assess needs and evaluate outcomes.



Source: WHO 2001.

Figure 2.1: Interactions between components of the International Classification of Functioning, Disability and Health

Cerebral palsy

Cerebral palsy is generally considered as a non-progressive neuro-developmental condition that occurs in early childhood and is associated with a motor impairment, usually affecting mobility and posture. Classification may be based on muscle tone, the anatomical distribution of the muscle impairment and/or the severity of the condition. However, given the considerable heterogeneity of the condition, a universally agreed definition of cerebral palsy has been difficult to establish. The most recently proposed definition of cerebral palsy, developed by Bax et al. 2005, incorporates the motor impairment component and non-progressive nature of cerebral palsy referred to in earlier definitions, along with other impairments commonly experienced by persons with cerebral palsy.

> Cerebral palsy describes a group of disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception and/or behaviour, and/or by seizure disorder (Bax et al. 2005).

The severity of disability associated with cerebral palsy is highly variable, depending on which limbs are affected and the type of impairment. Abnormal muscular control or spasticity (increased muscle tone) is the most common impairment among people with cerebral palsy; other impairments include dyskinesia (or involuntary movements), ataxia (an abnormality of muscle coordination) or hypotonia (diminished muscle tone) (Blair & Stanley 2001). Some people with cerebral palsy have multiple impairment types. Impairment may affect all four limbs (that is, quadriplegia) where the arms tend to be more affected than the legs, or mostly the legs (that is, diplegia). Impairment may also be more concentrated on one side of the body (right or left hemiplegia) with the arms again being more affected than the legs.

Classifying the severity of disability related to cerebral palsy has similarly been a challenging exercise. Recent classification schemes such as the Gross Motor Function Classification Scheme (GMFCS) (Palisano et al. 1997) and Bimanual Fine Motor Function Scale (Beckung & Hagberg 2002) focus more on functional abilities, rather than distribution and type of impairment, to evaluate severity. However, it has been proposed that a more extensive classification scheme comprising assessment of the nature, type and anatomical distribution of motor impairments, functional abilities, and the presence or absence of known associated impairments is more appropriate for properly assessing the severity of cerebral palsy (Bax et al. 2005).

‘CP-like’ disabilities

‘CP-like’ disabilities are also included within the scope of the project. CP Australia agencies have generally, over the last two decades, accepted clients who have similar disabilities (impairments, activity limitations or participation restrictions) to people with CP and hence are likely to benefit from a similar range of services.

The complex task of defining this group, for the purposes of this study, was done pragmatically, in the context of the population data available for analysis. The project’s Advisory Committee discussed this in detail and enabled the necessary series of decisions to be made. The approach decided on is outlined in detail in Chapter 4. Based on initial work, especially exploratory analysis of CP and CP-like disabilities in the population survey data, it was decided that acquired brain injury-related disabilities would be regarded as ‘CP-like disabilities’ for the purpose of the population data analysis components of the study. Specific inclusion of other conditions associated with CP-like disabilities (such as spinal cord injury, genetic disorders and muscular dystrophy) was not possible due to data limitations (see Section 4.2).

Acquired brain injury (ABI) has been used as an umbrella term to describe multiple disabilities arising from damage to the brain acquired after birth. It can occur as a result of accidents, stroke, brain tumours, infection, poisoning, lack of oxygen, degenerative neurological disease and more. Effects include deterioration in cognitive, physical, emotional and/or independent functioning (National Community Services Data Committee 2004). The main rationale for regarding ABI as a CP-like disability is that people with ABI, in particular traumatic brain injury, often have multiple, inter-related disabilities similar to CP disabilities, and thus often have similar needs for therapy and equipment to those of people with CP.

For the purposes of this study, baseline population estimates of people with CP-like disabilities are restricted to people aged under 45 years with ABI-related disabilities who had acquired main disabling condition before age 30, and who also had physical/diverse or hearing or speech disabilities (Figure 4.1). Decisions about the specification of this group were guided by a desire to focus on those people with early-onset disability, and with a disability profile similar to that typical of CP-related disability. To identify people with CP-like disabilities who are potential candidates for therapy and equipment, this estimate is further refined by selecting only those people who need personal assistance at least once a day with one or more core activities. This approach is consistent with the aim in this study of producing robust, useful and conservative estimates of need, unmet need and costs.

Therapy and equipment

Therapy aims to improve and/or maintain the wellbeing of an individual in society. Within the ICF framework, therapy may be defined as those interventions which aim to modify impairments, develop, maintain or improve the performance of activities, and/or develop, maintain or increase participation in life areas.

Defining the therapies 'in scope' for the project was important. Therapy has been described as:

> any intervention performed or prescribed by a therapist that promotes independence, improves functional ability and minimises the impact of disability (Cerebral Palsy Association of Australia 1997).

The therapist, in this context, may work in any of physiotherapy, occupational therapy, speech pathology, psychology or social work fields. As these professions reflect the range of services routinely provided by CP Australia agencies, it was agreed that they should constitute the core therapies for consideration in this study, even though additional disciplines can play a role in the management of people with CP and CP-like disabilities.

Therapy is directly linked to a client's needs and goals, which can change as they progress through childhood and adolescence into adulthood. Current therapeutic delivery models recognise this through an emphasis on the whole person rather than their impairments. Family-centred practice, person-centred planning and community capacity building are examples of such delivery models currently used in Australia. Within these models, therapists perform a variety of roles including direct clinical interventions, assessment, education and advocacy for the client.

The assessment, prescription and management of aids and equipment are an integral part of therapy. The international standard classification and terminology for technical aids for persons with disabilities defines technical aids as:

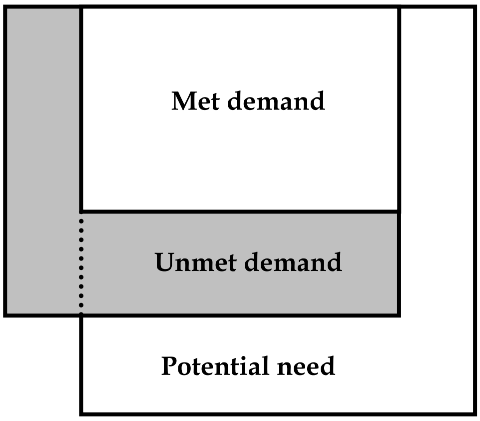
> any product, equipment or technical system used by a person with a disability, especially produced or generally available, preventing, compensating, monitoring, relieving or neutralising the impairment, activity limitation or participation restriction (ISO 2002).

Equipment is often used as a component of, or as an enhancement to, therapeutic intervention. Examples of equipment often used by persons with cerebral palsy include communication boards to promote communication and orthoses to improve mobility. Environmental modifications such as wheelchair ramps can act as an adjunct to therapy and equipment.

Need and demand

Need and demand are complex, multi-dimensional concepts. Need for services and assistance may be experienced and expressed in different ways by individuals with a disability, and by carers, communities, service providers and program managers.

Figure 2.2 illustrates the relationships between the concepts of met demand, unmet demand and potential need, and suggests approaches to the statistical indication of each.



Met demand indication. People receiving appropriate services and assistance.

Unmet demand indication. People:

- stating in surveys, letters and consultations that they have unmet needs—no service or inadequate service
- recorded on registers and waiting lists
- using services inappropriately, e.g. a manual wheelchair when it is recognised that an electric wheelchair is needed.

Not all people expressing a demand for services may be eligible (see shaded area to left of dotted line).

Potential need may be indicated in terms of:

- people or groups who appear disadvantaged in comparison to others
- people apparently meeting eligibility criteria and not receiving or demanding services
- society's goals or 'norms' which are not being met, e.g. housing, literacy or employment or, in this context, 'normal' physical and social functioning.

Source: Adapted from AIHW 2002.

Figure 2.2: Statistical indicators of demand and need for services

'Met demand' is indicated by numbers of people receiving an appropriate service (in this case, therapy or equipment). Data on service users are relevant to the estimation of met demand. However, some people receiving services may be receiving an inadequate level of service, or may be receiving an inappropriate service; in this study, the use of 'archetypal cases' helps with this estimation (see Chapter 8).

'Unmet demand' is indicated by numbers of people expressing the need for a service (therapy and/or equipment), but not receiving the service, or receiving an inadequate or inappropriate service. Demand can be identified through a population survey asking relevant questions, or through administrative means such as waiting lists, application processes or registers. Not all people who express need may be 'eligible' for therapy or equipment, and they are represented in Figure 2.2 by the shaded area to the left.

'Potential need' is not directly expressed, but may be inferred from data sources, for instance by comparing the characteristics of people receiving services, or demanding services, with those in apparently similar circumstances but not expressing the need for services. This approach is often used in service planning. On equity grounds, it is important to consider needs for services other than those actually expressed.

This broad conceptualisation of need and demand reflects the approach in this study. This is consistent with the concepts and terminology used in previous AIHW studies on need and demand for disabilities services, which were, in turn, developed with reference to and generally consistent with key literature (see discussion in AIHW 2002).

2.2 Estimating unmet need: relating concepts to data

To estimate unmet need for therapy and equipment, operational definitions of unmet need must be developed. That is, the study concepts must be related to the available data sources. This section provides these links. First, a broad overview of the data sources and the methods of analysis are presented, followed by tables indicating the relationships among the concepts, the data sources and links that facilitate the estimation of unmet need for therapy and equipment.

Main data sources and methods

As outlined in Section 1.3, four strands of data analysis were planned and undertaken.

- analysis of CP Australia client records, costs and waiting lists
- analysis of data about CSTDA services broadly, and comparisons of CP Australia agencies and their clients with other agencies and clients
- population data analysis
- developing and costing archetypal cases.

These different sources and methods are outlined briefly in this section. Several different data sources were used, both to ensure that all available information was brought to bear on this important project, and also to seek opportunities for confirming findings using data from different sources. This section also explains how the data sources can be related to one another and to the key concepts discussed in Section 2.1; the purpose of outlining these relationships is to illustrate the approach to integrated data analysis and calculation of key results.

National population data

The 2003 ABS Survey of Disability, Ageing and Carers (SDAC) is used as a main source for understanding the population under study and some of their needs.

The 2003 SDAC is the fifth in a series of national disability surveys; the first was conducted in 1981. The surveys have been specifically designed to collect comprehensive information about disability in the Australian population, with the aim of:

- measuring the prevalence of disability in Australia
- measuring the need for support of people with a disability and older people
- providing a demographic and socioeconomic profile of people with disabilities, older people and carers, which can be compared with the general population profile.

The 2003 survey covered people in both urban and rural areas in all states and territories, except for those living in remote and sparsely settled parts of Australia. It included people in both private and non-private dwellings, including those in cared accommodation establishments but excluding those in jails and correctional institutions. Detailed information about the 2003 SDAC and definitions is provided in Appendix B.

National data on disability services

The CSTDA NMDS is:

- a set of nationally significant data items or pieces of information that are collected in all Australian jurisdictions
- an agreed method of collection and transmission.

The purpose of the CSTDA NMDS collection is to facilitate the annual collation of nationally comparable data about CSTDA-funded services and to obtain reliable, consistent data with minimal load on disability service providers.

From 1994 to 2002, this information had been collected only on one snapshot day in the year. In recognition of the changing information needs in the disability services field, the National Disability Administrators (now known as Disability Policy and Research Working Group) and the AIHW conducted redevelopment work on this collection. The most significant change brought about by the redevelopment of the collection was that data were to be collected on a full-year, ongoing basis. The first full financial year of data collection took place between 1 July 2003 and 30 June 2004.

Services and assistance of relevance to people with a disability include:

- generic services and assistance available to the whole population, including health, housing, transport, education and employment services
- income support, including the Disability Support Pension and Carer Allowance
- specialist disability services
- equipment or environmental modifications
- informal support from family and friends.

Specialist disability support services funded under the CSTDA are thus situated in this mosaic of services and assistance. These specialist services may ameliorate disadvantage associated with any of the components of disability—impairment, activity limitation, participation restriction or environmental barriers.

The five broad CSTDA service groups are accommodation support, community support, community access, respite, and employment. Community support services are of particular interest to this study—this group includes therapy support for individuals and early childhood intervention.

Data held by CP agencies

CP Australia organisations are at varying stages in establishing databases that are more specific to therapy and that record activity related to client services. Some states have reasonably well established databases and can provide a range of additional information related to allied health services delivered to clients. Organisations in several states of Australia are in the final stages of establishing similar specific client recording systems. In some of the CP Australia organisations, client recording systems remain paper-based and contain less detailed information about therapy related services provided to clients.

The AIHW made special data requests of CP organisations in several jurisdictions to gather information on clients, including diagnosis, measures of function, hours of therapy received, and numbers and characteristics of clients on therapy and equipment waiting lists.

Archetypal cases

The archetypal cases component of the project is another key source of information for estimating the cost of unmet need for therapy for people with CP and like disabilities.

Archetypal cases are hypothetical client profiles, intended to represent key groups in the client population. Case stories for 18 archetypal cases were developed by extracting common themes and goals after examining a number of client files; they reflect the needs and circumstances of real 'typical' clients, but are not identifiable as any individual client.

The case stories fit within nine archetypal case categories defined by age group and disability severity, which are two key factors in predicting need for therapy and equipment, and are present as data items in national data sources.

The archetypal cases were used as a vehicle for gathering information from therapists about the therapy and equipment needs of different client groups and the extent to which these needs are met. This information is brought together with data from the SDAC and the CSTDA NMDS in order to estimate the cost of meeting unmet needs for therapy. The methodology is explained in detail in Chapter 8.

Bringing together information from the key data sources

Each data source was scrutinised for what it could contribute to the project method. This evaluation of data sources sought data items that were:

- relevant to the identification and estimation of unmet needs for therapy and equipment; and/or
- common to more than one data source, so as to relate the data sources and use them to complement each other and fill in the gaps or areas of weakness in each.

The main areas of strength and weakness of each of the data sources can be summarised as follows.

- The SDAC provides demographic and disability information that can be used to identify and profile the population with cerebral palsy and like disabilities; there is information on met and unmet need for assistance (but not therapy), but no cost data. See Chapters 4 and 7.
- The CSTDA NMDS provides a range of information on users of CSTDA-funded services, including demographic items, disability and support needs information, and services received. There is some high-level information on service costs, but no information on unmet need. It is not possible to directly identify service users with CP and like disabilities in the broader CSTDA service user population. However, CP agency services were able to be separately identified in analyses for this study, with CP Australia agreement and NDA (now known as Disability Policy and Research Working Group) cooperation. See Chapter 6.
- Additional CP Australia agency records provide some information that can be used to augment the data available from the CSTDA NMDS, in particular on diagnosis, measures of function, hours of therapy received, and numbers and characteristics of clients on therapy and equipment waiting lists (that is unmet need). Information is available only for some states; in general, this information is not recorded in a nationally consistent way. See Chapter 6.

- The archetypal cases provide detailed profiles of typical clients and the type, quantity and cost of therapy and equipment they require to meet their needs. This project component also provides therapists' estimates of levels of unmet therapy need among people with CP and like disabilities in contact with specialist disability services. The data, being artificially constructed, were made useable by the inclusion of 'data hooks' to relate them to the SDAC and the CSTDA NMDS. See Chapter 8.

The key to successful analysis involved finding enough common data items or 'hooks' so that data from the various sources could be brought together to provide a comprehensive national picture of the nature and cost of unmet need for therapy and equipment. Data items relating to support needs emerged as a powerful means of relating data from the different sources, particularly because both the CSTDA and the SDAC have been developed to be broadly consistent with the conceptual framework of the ICF.

The CSTDA NMDS includes a question about how often the service user needs personal help or supervision with activities or participation in nine life areas, which correspond well to the ICF domains for activities and participation: self-care; mobility; communication; interpersonal interactions; learning, applying knowledge, and general tasks and demands; education; community (civic) and economic life; domestic life; and working. Response categories are: unable to do or always needs help; sometimes needs help/supervision; does not need help or supervision but uses aids and/or equipment; and not applicable.

In the SDAC, people with a disability were asked questions about their need for assistance with various tasks associated with daily activities. The tasks are grouped into 10 types of activities which also relate well to the ICF activity and participation domains. Self-care, mobility and communication are described as 'core activities', while the other seven activities are 'non-core activities' (health care, housework, property maintenance, paperwork, meal preparation, transport, and cognition and emotion). Four levels of core activity limitation are determined (See Appendix B for detailed definitions):

- profound—unable to do or always needs assistance
- severe—sometimes needs assistance, or has difficulty understanding or being understood by family or friends, or can communicate more easily using sign language or other non-spoken forms of communication
- moderate—does not need assistance, but has difficulty
- mild—has no difficulty but uses aids or equipment because of disability; or cannot perform the activities of easily walking 200 metres, walking up and down stairs without a handrail, easily bending to pick up an object from the floor, and using public transport; or can use public transport but needs help or supervision; or needs no help or supervision but has difficulty using public transport.

These four levels of core activity limitation in the SDAC match well with the CSTDA support needs response categories. In addition, the SDAC provides more detailed information on how frequently assistance is needed (e.g. 6 times a day or more, 3 to 5 times a day, etc.).

In the archetypal cases, the 18 case stories fit within nine archetypal case categories defined by age group and disability severity. Analysis of the case stories in terms of need for support with self-care, mobility, and communication (Table A8.2) revealed that the 'severe disability' case stories could be defined in terms of both SDAC and CSTDA data on support needs:

- In SDAC terms, archetypal cases 'severe' case stories can be identified as:
  - needs help at least 3 times a day in at least one core area, and
  - needs help or uses aids in at least two core activity areas.
- In CSTDA terms, archetypal cases 'severe' case stories can be identified as:
  - always needs help in at least one core area, and
  - needs help or uses aids in at least two core activity areas.

Need for help with self-care, mobility and communication has been used in the data analysis chapters of this report as an indicator of need for therapy and equipment, and as a means of linking data from the various sources in order to produce costed estimates of unmet need for therapy (see for example Sections 4.3 and 9.3, and Table A8.2).

Relating key concepts to data sources

Table 2.1 relates:

- disability concepts, the life areas in which people participate or perform activities (Column 1); to
- types of therapy (column 2) and equipment (column 3) that can be used to promote goals in these areas; to
- data content in the population survey (column 4).

An interdisciplinary approach to therapy is currently recognised as best practice in the field. This approach involves professionals working towards shared goals and implementation plans, but still implementing their own sections of the plan independently (see Section 3.4). In recognition of the multidimensional nature of disability, interventions are often targeted to all ICF components (body function/structures, activity and participation and the environment) and therapy performed in one area may have 'flow on' effects in another (such as therapy directed towards non-verbal gestures will improve interpersonal interactions). Disciplines which are most likely to take a leading role in and/or have a particular focus on a given life area have been underlined in Table 2.1. Examples provide a picture of some therapeutic interventions within the scope of the project.

This table guides the search for population indicators of need for therapy and equipment in the population data (Chapter 7). The ICF broad domains for activities and participation have been used to guide the construction of the relationship framework in Table 2.1. The table does not reflect the possible feedback relationships between therapy and equipment—that is the possibility that meeting needs in one area may diminish needs in another, or that unmet need in one area may give rise to greater demand in another area.

Although the table does not refer to the CSTDA NMDS, questions relating to need for assistance with core activities in the CSTDA NMDS collection are designed to be similar to the SDAC questions to allow some comparisons between the two data sources.

Table 2.2 relates:

- disability concepts relating to body functions (column 1); to
- data content in the population survey (column 2); to
- types of therapy and equipment that can be used to address limitations in these functions.

These two tables illustrate that therapy and equipment potentially relate to all ICF domains for activities and participation, and body functions.

Table 2.1: Relating disability (activities and participation), to therapy and equipment, and to the population data source

Individual's life areas(a)	Therapy(b)(c)	Equipment(c)	ABS 2003 disability survey activity and participation questions
Learning and applying knowledge	Speech pathology (receptive language, memory, listening skills), **occupational therapy**, psychology (problem solving), physiotherapy (learning sensory experiences, advice to teachers to facilitate learning)	Reading aids (book holders, page turners)	Difficulty learning and understanding
General tasks and demands	**Occupational therapy** (organisation skills), psychology (counselling to handle stress), physiotherapy (practicing general tasks)	Clocks (voice recording alarm clock)	Paperwork Decision making or thinking through problems
Communication	**Speech pathology** (expressing messages)	Communication aids (communication boards and dictionaries), telephones (large button telephones)	Communication Speech
Mobility	**Physiotherapy** (gait training), occupational therapy (training in the use of aids and equipment)	Mobility aids (wheelchairs, scooters), home adaptations (ramps), vehicle accessories (electric windows, car door opener)	Mobility; Public and private transport
Self-care	**Physiotherapy** (eating/drinking positioning), **occupational therapy** (assessment and intervention to improve dressing), speech pathology (oral sensorimotor training)	Equipment for personal use in daily living (toilet support, hoists, cutlery, pressure cushions)	Self-care Health care
Domestic life	**Occupational therapy** (food preparation), physiotherapy, social work (assistance with housing)	Equipment of daily living/household aids (switches, modified utensils, reaching aids)	Housework Property maintenance Meal preparation
Interpersonal interactions and relationships	**Social work** (support of families and clients), **psychology** (counselling), occupational therapy (peer relationships), speech pathology (training of communication partners or advice)		Cognition and emotion Making or maintaining relationships Coping with feelings or emotions
Major life areas (education, work, economic life)	Speech pathology (education for teachers), occupational therapy (work place skills and play therapy, adaptations to educational and work structures), psychology (vocational assessments), physiotherapy (participation in school physical activities), social work (advice to families and teachers on child's adjustment)	Educational and vocational equipment (software, pencil grips, sloped desks, keyboards, mouse options)	Schooling Employment
Community, social and civic life	Physiotherapy (leisure activities such as wheelchair sports, swimming), occupational therapy (community education on improving physical access), social work (advocacy for people with disabilities)	Building adaptations, play equipment (switch toys), sports and leisure equipment (swimming equipment such as resistance rings, floats)	Community participation

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

(b) Disciplines that are most likely to take a leading role in and/or have a particular focus on a given life area are bolded.

(c) Specific therapy interventions and equipment items given in parentheses are examples only.

Table 2.2: Relating disability (body functions), to therapy and equipment and to the population data source

Body functions[a]	ABS 2003 disability survey activity and participation questions: indicators of need for therapy and/or equipment	Therapy and equipment
Mental functions	Difficulties learning or understanding things Nervous or emotional condition Need for help or supervision due to mental illness (also E code—general indicator of need for assistance) Difficulties coping with feelings or emotions	Occupational therapy (interventions to improve attention), speech pathology (receptive language), psychology (cognitive behavioural methods), social work (counselling on psychosocial issues).
Sensory functions and pain	Loss of sight—including complete absence or loss Loss of hearing—including complete absence or loss Chronic or recurrent pain or discomfort (including whether restricted in 'everyday activities')	Occupational therapy (visual and sensory stimulation), physiotherapy (developing proprioception), speech pathology (oral sensorimotor therapy), multidisciplinary (pain management), orthoptists[b]
Voice and speech functions	Speech difficulties—including complete absence or loss	Speech pathology (oromotor function, expressive language), physiotherapy (muscle strengthening).
Functions of the cardiovascular, haematological, immunological and respiratory systems	Shortness of breath or breathing difficulties (including whether restricted in 'everyday activities')	Physiotherapy (fitness and respiratory training)
Functions of the digestive, metabolic and endocrine systems	Indirect—does anyone help or supervise with managing continence[c]	Speech pathology (saliva management, mealtime management), physiotherapy (muscle control, strengthening pelvic floor), occupational therapy, psychology (toilet timing, training programs) modified toilet/commode chairs, continence aids.
Genitourinary and reproductive functions	Indirect—does anyone help or supervise with managing continence[c]	Occupational therapy, psychology (toilet timing, training programs) modified toilet/commode chairs, continence aids, physiotherapy, occupational therapy (assistance with menstruation management) continence aids
Neuromusculoskeletal and movement-related functions	Incomplete use of arms/fingers Incomplete use of feet/legs Difficulty gripping or holding things	Physiotherapy (fine motor control, range of movement and muscle strengthening), occupational therapy, splints, casts and orthoses, orthotists[b]
Functions of the skin and related structures	May be captured in response to questions on 'receiving treatment or medication for any other long-term conditions or ailments and still restricted in everyday activities' or 'disfigurement or deformity'	Occupational therapy (scar management, skin hygiene), physiotherapy (pressure care in positioning)
Any body function	May be captured in response to: Whether has had head injury, stroke, or any other brain damage	

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

(b) Services provided by allied health professionals such as orthoptists and othotists may play a role in the therapy of people with CP and CP-like disabilities, but are not considered within the scope of the project.

(c) Incontinence may be defined as a body function impairment (to the bladder or bowel) or as an activity limitation where help or assistance is required in toileting or managing the incontinence.

3 Literature review

This chapter uses a review of the literature to examine the components and nature of therapy, and the perceived effectiveness of therapy options available to persons with cerebral palsy and like disabilities. The chapter starts with a summary of definitions and classification schemes developed to identify and measure the severity of cerebral palsy (Section 3.1), followed by available information on the incidence of cerebral palsy, and survival rates of persons with cerebral palsy, in Australia and overseas (Section 3.2). A description of the functional and health status of children and adults with cerebral palsy, in Section 3.3 provides context for a more detailed discussion of therapy in subsequent sections.

Section 3.4 explores the concept of therapy, describing the different definitional approaches that may be taken to conceptualise therapy, while Section 3.5 describes the range of frameworks under which therapy provision may be applied. The variation in therapeutic approaches specific to certain stages of life (that is, early childhood, school age, adolescence and adulthood) is discussed in Section 3.6.

Finally, section 3.7 reviews current research on the effectiveness of therapy, including consideration of the efficacy of specific therapeutic interventions and the intensity of therapy, whether certain subgroups benefit more from therapy than others, as well as addressing strategies for the future measurement of effectiveness of therapy.

3.1 Definition and classification of cerebral palsy

A universally accepted definition that '…capture/s the essential core and unvarying nature of cerebral palsy…' (Shevell & Bodensteiner 2004) has continued to elude clinicians and researchers, in part due to the heterogeneous nature of the condition. The lack of definitional agreement has had a significant impact on cerebral palsy research. During the keynote address of the 2006 International Cerebral Palsy Conference, Martin Bax (one of the most prolific authors in the field of cerebral palsy) claimed that it is likely that cerebral palsy is not one condition but in fact many neurological conditions ill-conceived under the same umbrella term.

Cerebral palsy can be broadly defined as a neuro-developmental condition that occurs in early childhood and is associated with a motor impairment.[1] Earlier definitions of cerebral palsy, presented in Box 3.1, all emphasised a non-progressive condition characterised by an impairment of movement and posture, due to a lesion or anomaly of the brain that occurred during a child's early development. By what age that injury must occur to the brain for the condition to be considered cerebral palsy is yet to be resolved, however, with some advocating the injury to have occurred by 2 years of age and others by 5 years of age.

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[1] Some of the terms used in this chapter have not been modified to reflect ICF terminology, for example 'motor impairment'. This has been done to remain true to the literature but also to retain some of the key terms that are used regularly in the cerebral palsy field.

Box 3.1: Selected definitions of cerebral palsy

'A persisting but not unchanging disorder of movement and posture, appearing in the early years of life and due to a non-progressive disorder of the brain, the result of interference during its development'
(Mac Keith et al. 1959)

'A disorder of movement and posture due to a defect or lesion of the immature brain…For practical purposes it is usual to exclude from cerebral palsy those disorders of posture and movement which are (1) of short duration, (2) due to progressive disease, or (3) due solely to mental deficiency' (Bax 1964)

'An umbrella term covering a group of non-progressive, but often changing, motor impairment syndromes secondary to lesions or anomalies of the brain arising in the early stages of development' (Mutch et al. 1992)

Prompted by a range of factors, including developments in neurobiology, an improved understanding of the antecedents and correlates of cerebral palsy, and new approaches to conceptualising disability and functioning, the International Workshop on Definition and Classification of Cerebral Palsy met in 2004 to develop a more inclusive definition of cerebral palsy.

The new consensus definition states:

> Cerebral palsy describes a group of disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behaviour, and/or by seizure disorder (Bax et al. 2005:572).

This definition again highlights the motor impairment component of cerebral palsy, brought about by some form of injury to the developing brain. It also encompasses the conceptualisation of disability in the ICF, whereby activity limitation is conceived as a component of disability. The definition also expands the notion of cerebral palsy by recognising other associated impairments (for example, sensory and cognitive) often experienced alongside motor impairment. The definition has been published for consideration by a wide range of cerebral palsy specialists and builds upon the work of earlier definitions.

The severity of cerebral palsy is highly variable, depending on which limbs are affected and the type of movement impairment. These two factors combined form the various classifications of cerebral palsy. Spasticity, or muscle stiffness, is the most common type of movement disorder among people with cerebral palsy. Other movement impairments include dyskinesia, which comprises two sub-types, dystonia (or fluctuating muscle tone) and athetosis (or stormy involuntary movement), and the most rare movement disorder, ataxia (or muscle shakiness) (Blair & Stanley 2001). Some persons with cerebral palsy have multiple movement impairments. The distribution of the impairment may affect all four limbs (that is, quadriplegia) where the arms tend to be more affected than the legs, or mostly the legs (that is, diplegia). Impairment may also be more concentrated on one side of the body (right or left hemiplegia) with the arms again being more affected than the legs.

The classification of cerebral palsy is similarly complex. The traditional approach to classifying cerebral palsy relies on identification of the distributional pattern of affected limbs plus the type of tone or impairment of movement. Groupings are usually based on the predominant motor impairment but as a substantial number of persons with cerebral palsy experience more than one motor impairment, it has been proposed that a more clinically and aetiologically sound classification should include identification of all impairments of tone or motor function (for example, Sanger et al. 2003).

As mentioned earlier with definitional confusion, there has also been inconsistent use of classification terms. Different experts and diagnosticians can disagree on the classification of cerebral palsy in the same person, particularly where the terms hypotonia, athetosis and dystonia movement disorders are used.

More recently, classification schemes[2] specifically designed to rate the severity of cerebral palsy have focused on functional abilities, partly in response to the ICF and its emphasis on the multi-dimensional nature of functioning and disability but also to increase reliability among users. The internationally recognised and standardised GMFCS measures severity of mobility limitation. The GMFCS uses a 5-level scale to differentiate self-initiated ability to walk and execute movement transition, with or without mobility aids and in different environments (Palisano et al. 1997). Level 1 classifies a child as being able to walk without restriction but who has limitations in more advanced gross motor skills. Level 5 describes where a child is considered to have a severe limitation in self-mobility even with the use of aids and equipment. Another recent classification scheme is the Manual Ability Classification System (Arner et al. in press), which measures hand and arm function to compliment the GMFCS scale A. Level 1 classification means the arm handles objects easily and successfully, while Level 5 describes an arm that does not handle objects and has severely limited ability to perform even simple actions.

It is widely accepted that it is essential to identify the distribution and severity of movement disorder in a person with cerebral palsy, in order to determine appropriate management options (Koman et al. 2004). The severity of a person's cerebral palsy is linked to their prognosis and potential for improvement from intervention (Wood & Rosenbaum 2000). Factors contributing most to a person's potential are the severity of the movement disorder and the distribution of involvement across the body (Bartlett & Palisano 2002).

Work on accurate classification systems is underway by Australian cerebral palsy registries but are not yet complete. The 2004 International Workshop on Definition and Classification of Cerebral Palsy recommended that any classification of cerebral palsy include four primary dimensions, as follows:

- motor impairments
  - nature and typology of motor impairment (tonal abnormalities and movement impairment, for example spasticity)
  - functional motor abilities
- associated impairment (presence or absence of seizures, vision or hearing impairments, cognitive impairment, attention deficit, emotional or behavioural problems)

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[2] There is some inter-changeability in the use of the terms 'classification scheme' and 'clinical instrument' in the literature. While the GMFCS and MACS are described as classification schemes, their primary function is as a clinical tool to measure level of functioning among children with cerebral palsy in order to compare severity.

- anatomical and radiological finding
    - anatomical distribution of motor impairment
    - radiological findings
- causation and timing (if known).

Bax et al. (2005) argue that new classification schemes will facilitate better understanding of cerebral palsy, and hence an improved management of the condition. Some dimensions, such as radiological findings, are as yet not well catered for and further work is required to develop appropriate classification schemes for each dimension.

3.2 Incidence of cerebral palsy

Estimating the incidence of cerebral palsy is impeded to some extent by the absence of a universally applied definition and some inconsistency in how severe the condition needs to be for consideration in estimates (Mutch et al. 1992). An additional factor also affecting the estimation of incidence, and comparison of estimates between different population groups, is the absence of a minimum or maximum age within which the label of cerebral palsy can be applied (Blair & Stanley 2001). The minimum age is particularly critical in estimating the prevalence of severe cerebral palsy since risk of infant mortality is greater among this group and differential use of a minimum age between clinicians may see differential rates of severe cerebral palsy. The use of all live births, rather than infant survivors, can also affect the incidence among preterm babies (but not the cerebral palsy population as a whole) (Blair & Stanley 2001).

Most of the published estimates derive either from registers of children with cerebral palsy or surveys of all live births, generally in a defined geographic region, over a defined time period, and using various ascertainment methods to identify children with cerebral palsy. These estimates all focus on incidence (although termed as prevalence in the literature); actual prevalence estimates of cerebral palsy have not been published.

There is general consensus that the incidence of cerebral palsy is around 2–3 per 1,000 live births (see Winter et al. 2002), which makes it the most common physical disability in childhood (Rosenbaum 2003). Incidence rates have fluctuated since being recorded in the 1960s but remain essentially the same despite significant advances in obstetric and neonatal care (Blair & Watson 2006). Rates were generally lower in the 1970s and then increased until the mid- to late 1980s, particularly among pre-term and low birthweight babies (low birthweight babies weight between 1,000–1,499 g and very low birthweight babies below 1,000 g) (Blair & Watson 2006). In Western Australia, rates of cerebral palsy rose between 1975 and 1985 among children whose birthweight was less than 1500 g, with no change in rates for other birthweight groups, except for a slight decline in the 1500–1999 g group (Stanley & Watson 1992). Similar patterns were reported for western Sweden (pre-term: Hagberg et al. 1984, 1989, 1993) and the United Kingdom (low birthweight: Colver et al. 2000; Emond et al. 1989; Pharoah et al. 1996) and predicted for the United States (low birthweight: Bhushan et al. 1993). A review of data from various European registers also found an associated increase in the incidence of cerebral palsy with low birthweight (SCPE 2000). However, inconsistent patterns between these studies were also apparent; for example, only in Sweden did a rise in cerebral palsy occur regardless of birthweight and term of delivery, although rates were higher in pre-term babies (Hagberg et al. 1989). Further confounding identification of a consistent trend were results from a US study based on 1-year survivor cohort data which found cerebral palsy rates only rose, albeit slightly, among normal weight babies, and not among low or very low birthweight babies (Winter et al. 2002).

The early to mid-1980s peak in cerebral palsy rates have since started to decline, with significant falls recorded for Scandinavia (western Sweden: Himmelmann et al. 2005; Denmark: Topp et al. 2001; Norway: Meberg & Broch 1995), the extended Oxford region of England (Surman et al. 2003) and Slovenia (Kavcic & Perat 1998), but have not yet dropped to reach the low measured in the 70s (Blair & Watson 2006). In Western Australia, however, no decline has occurred among very low birthweight babies (Watson et al. 1999) and, in northern England, cerebral palsy rates have continued to rise into the early 1990s (Colver et al. 2000).

The initial increase in cerebral palsy has largely been attributed to increased survival rates of babies, particularly low and very low birthweight and pre-term babies, associated with changes to obstetric, perinatal and intensive neonatal care. But the reasons behind the subsequent decline in several countries have not been fully explored in the literature, although Topp and colleagues (2001) have suggested that the decline in cerebral palsy incidence in Denmark may have been influenced by a change in treatment in neonatal intensive care units, specifically a decline in the use of mechanical ventilation.

3.3 Survival rates and functional and health status

Survival rates

The life expectancy of persons with cerebral palsy has improved since the middle of the twentieth century, which Blair and colleagues (2001) attribute to changes in various medical and social factors, such as improved intensive care procedures, use of antibiotics, greater integration of people with disabilities into the community, and a better responsiveness to the rights of people with disabilities. These improvements have meant more and more people with cerebral palsy are living into their adult years.

Using the Western Australian Cerebral Palsy Register, Blair and colleagues (2001) estimated mortality rates for persons with cerebral palsy born between 1956 and 1994. In that time period, 6% of all persons with cerebral palsy died before the age of 5 years and another 11% died between the ages of 5 and 40 years. The risk of mortality before the age of 30 years was significantly higher for persons with a severe intellectual or motor impairment, or who had multiple severe impairments. Nonetheless, it was predicted that most persons with cerebral palsy now live to their adult years (where the condition is poorly understood—Rosenbaum 2003). Those with a profound intellectual impairment however have lower survival rates.

Overseas-based studies have also reported survival rates. Survival to 20 years for persons with cerebral palsy living in north-east England was 87% for males and 89% for females (Hutton & Pharoah 2002) and to 40 years, 83% and 85% respectively (Hutton et al. 2000). Among people with cerebral palsy in British Columbia, Canada, survival to 30 years was 87% (Crichton et al. 1995). All overseas studies found an association between increased mortality risk and severity of impairment(s) (Crichton et al. 1995; Evans et al. 1990; Hutton et al. 1994, 2000; Strauss et al. 1998), particularly severe intellectual impairment and motor impairments. However, quite different survival rates were found between studies. For example, two UK studies reported the survival rate to age 30 years for persons with cerebral palsy who also had a severe intellectual impairment ('cognitive disability') to be around 65% (Hutton et al. 1994, 2000). However, the same two studies estimated survival rates to age 30 years for persons with a 'severe manual disability' to be 60% and 47% respectively and for persons with mobility impairment(s) to be 63% and 50%. It is possible that the composition of study populations and how disability is defined between studies explains some of this anomaly. In addition, whole country population registers for cerebral palsy do not yet exist and thus sampling bias may be occurring.

Functional and health status

Children and youth

The functional abilities of children and youth with cerebral palsy vary considerably from person to person, largely due to the heterogeneous nature of the condition. However, there are associations between impairment type and severity and activity limitations and participation restrictions.

Among children, more severe cerebral palsy is associated with more severe activity limitations (specifically in mobility and self-care) and participation restrictions (for example, education, social relations and other social functions) (Beckung & Hagberg 2002; Lepage et al. 1998; Østenjø et al. 2003).[3] Studies have shown that Swedish children with severe movement impairments tend to have severe or complete mobility limitations and severe or complete restrictions in education and maintaining wider social relations (Beckung & Hagberg 2002). In Canada it was found that cerebral palsy significantly disadvantaged children's participation in recreational pursuits, the community and education, especially so for those with quadriplegia and diplegia (Lepage et al. 1998).

Many of the health conditions and impairments commonly associated with cerebral palsy also affect functioning. The impact of the comorbid conditions seen with cerebral palsy is at least as significant as the motor impairments (Rosenbaum 2003). In particular, epilepsy, intellectual impairment and, to some extent, visual impairments have been found to impact on a child's participation in mainstream education and their ability to socialise outside the immediate family (Beckung & Hagberg 2002). Speech and language impairments and 'understanding difficulties' may also be in part responsible for the variability in activity limitation and participation restriction among children with cerebral palsy (Lepage et al. 1998). Children with persistent functional limitations, in turn, can have considerable social and behavioural difficulties (see, for example, Cadman et al. 1987), which may lead to their experiencing peer rejection, a lack of friends and victimisation (Yude & Goodman 1999).

The emotional functioning of children and adolescents with cerebral palsy, specifically their feelings of self-esteem, may be somewhat lower than their peers who do not have a disability. However, variable results from studies examining self-esteem among children with cerebral palsy suggest that lowered self-esteem cannot be considered a universal trait to this group (Shields et al. 2006). A review of six studies by Shields and colleagues (2006) identified teenage girls as being most at risk of self-esteem issues, particularly regarding their physical appearance and social acceptance. For example, among Canadian teenagers

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[3] Beckung & Hagberg (2002) and Østenjø et al. (2003) determined severity using the GMFCS; Lepage et al. (1998) based their measure of severity on impairment of muscle tone.

aged 13–18 years, girls with cerebral palsy had significantly lower scores for physical and social self-esteem than boys with cerebral palsy and girls who did not have a disability (Magill & Hurlbut 1986). This lowered self-esteem among girls compared with boys with cerebral palsy is opposite to what is observed among teenagers in general, that is, boys tending to have lower self-esteem. Other studies have found little or no difference between the sexes but identified other factors affecting self-esteem, such as the perceived impact of disability (Manuel et al. 2003) or whether children were in mainstream or special schools, with the former reporting higher self-esteem (Mrug & Wallander 2002).

While in many cases children and adolescents reported similar levels of self-esteem as their peers without a disability, some did acknowledge experiencing barriers to social participation. For example, in a study of 11–16 year olds with physical disabilities, including cerebral palsy, adolescents with cerebral palsy indicated they found it harder to make friends and spent less time with friends outside of school (Stevens et al. 1996). The friendships they had were perceived as less intimate than those experienced among children without a disability and generally less satisfying.

The health status of children and youth with cerebral palsy has been documented most recently by Wake et al. (2003) and Liptak et al. (2001) who used the Children's Health Questionnaire to compare health and health-related quality of life among children in Australia and the United States of America (USA) respectively. Both studies found the physical health of children with cerebral palsy to be significantly poorer than other children, with functioning scores especially low for physical functioning, physical roles associated with social activities (that is, more limited in school work or activities with friends) and general health. Pain was another factor much worse for children with cerebral palsy in the USA, as it was for Australian children with cerebral palsy, although the effect was not as strong. In the Australian study, health status scores were also lower for children with more severe forms of cerebral palsy compared with children with mild cerebral palsy. A new instrument has been developed in Australia to specifically measure the quality of life of children with cerebral palsy. The Cerebral Palsy Quality of Life instrument explicitly measures condition-specific symptoms such as pain (Waters et al. 2006) and will provide useful insights in future research.

Adults

While many of the functional challenges children with cerebral palsy face are also experienced by adults with cerebral palsy, the transition into adulthood introduces new or more complex life issues (van der Dussen et al. 2001). These include employment, social integration, living arrangements, and development of companion and intimate relationships, as well as continued or worsened limitations in mobility, communication and self-care. Consequently, investigation into functioning among adults with cerebral palsy often focuses on these life areas, alongside more common activities of daily living.

Recent studies looking at functioning among adults with cerebral palsy have generated a somewhat contrasting picture of the level of participation experienced. Table 1 lists the findings from five recent studies describing the functioning of adults with cerebral palsy living in Australia (Balandin & Morgan 1997), the UK (Stevenson et al. 1997); the USA (O'Grady et al. 1995), Italy (Bottos et al. 2001) and the Netherlands (van der Dussen et al. 2001). The variability of participation in specific life areas may be explained in part by the small number of people included in each study (less than 300), and differences in, for example, their average age, severity of impairment(s) and opportunities available for participation.

Table 3.1: Living arrangements, marital status, education and daily activity of adults with cerebral palsy, Australia, Italy, USA, UK and the Netherlands (per cent)

	Balandin & Morgan 1997 Australia	Bottos et al. 2001 Italy	O'Grady et al. 1995 USA	Stevenson et al. 1997 UK	van der Dussen et al. 2001 The Netherlands
	n = 279, 30–74 years	**n = 72, 19–65 years**	**n = 117, 17–51 years**	**n = 42, 20–22 years**	**n = 80, 21–31 years**
Living arrangements					
Independent[(a)]	18.6	12.5	47.9	7.1	32.5
With parents	78.9	75.0	30.8	81.0	37.5
With others		. .	n.p.	. .	30.0
'Institutions'[(b)]	2.5	12.5	19.6	11.9	. .
Marital status					
Married	n.p.	11.3	10.3	n.p.	12.5
Not married	n.p.	88.7	82.1	n.p.	87.5
Level of education achieved					
No schooling	n.p.	9.0	. .	n.p.	. .
Primary or not completed secondary	n.p.	25.4	23.9	n.p.	47.5
Secondary	n.p.	55.2	10.3	n.p.	46.2
Tertiary or vocational	n.p.	10.4	54.7	n.p.	7.5
Daily activity					
Paid employment	32.6	17.7	48.7	7.1	20.0
Sheltered employment	. .	16.1	n.p.	. .	16.3
Day activity centre	30.5	n.p.	n.p.	31.0	41.3
Education/training	n.p.	n.p.	n.p.	38.1	11.3
Other	5.1	n.p.	n.p.	n.p.	10.0
No formal activity/not employed[(b)]	23.3	66.1	51.3	23.8	n.p.

(a) 'Independent' living was defined either as living alone (for example, Balandin & Morgan 1997; Bottos et al. 2001 and van der Dussen et al. 2001) or living separately from their parents (O'Grady et al. 1995; Stevenson et al. 1997). It was not reported whether people in the latter group lived alone or with persons other than their parents.

(b) Institutions were not defined in sources.

(c) Percentage refers to persons not involved in a formal activity or are retired (Balandin & Morgan 1997); not involved in a formal activity (Stevenson et al. 1997) or unemployed (Bottos et al. 2001; O'Grady et al. 1997).

Note: Where applicable, not stated data are excluded.

n.p. not published

Many adults with cerebral palsy lived in private accommodation —independently, with their parents or 'with others'. However, in some of the studies a substantial proportion lived in cared accommodation, as many as 20% of adults with cerebral palsy in northern California, USA doing so. The majority had not married or established de facto relationships (over 80%).

Participation in education for the majority of adults with cerebral palsy meant completion of secondary education and, for some, tertiary or other higher level education as well. Around a quarter of adults with cerebral palsy in Italy and the US study, and just under half in the Netherlands study, however, did not complete secondary school or only completed primary level education.

Transition to employment has been mixed. While 33% and 36% of adults with cerebral palsy in Australia and the Netherlands, respectively, were in paid employment, only 18% in Italy and 7% in the UK reported being in paid employment. Sheltered employment accounted for the employment of some of the Italian adults' employment but many adults, in the UK and the Netherlands particularly, were involved in day activity centres instead.

Only Stevenson and colleagues (1997) looked at social participation among adults with cerebral palsy, which they compared with similarly aged adults who did not have a disability. The former group were significantly more socially isolated in their pursuit of social and leisure activities, both in terms of actual participation, and the availability of environmental factors enabling them to socialise, such as close friends or appropriate facilities. Adults with cerebral palsy also expressed greater anxiety about socialising, which further impeded their participation in social and other activities.

The health of adults with cerebral palsy appears from the limited available literature to be reasonably good. Around 31% of adults with cerebral palsy in Liverpool, UK reported very good health (Stevenson et al. 1997) and 46% of adults in Italy did not have any significant health problems (Bottos et al. 2001). Of significant issues reported, the most common was feeding difficulties (32%), followed by epilepsy (25%), bowel and bladder management problems (13% each) and speech and visual impairments (12.5% each). No serious health conditions were reported by 101 adults with cerebral palsy living in and around San Francisco, USA (Murphy et al. 1995), although there was a greater prevalence of incontinence compared with adults without a disability. Since most of the adults with incontinence were also mobility impaired, it was considered the incontinence was largely a result of that mobility limitation, that is, they were not being able to get to or prepare for the toilet in time.

Unlike children, there has been little research attention on emotional functioning among adults with cerebral palsy. Magill-Evans and Restall (1991) asked participants of an earlier study on self-esteem among adolescents (with cerebral palsy and without a disability) about their self-esteem seven years later. Adult males with cerebral palsy (mean age 22.7 years) had self-esteem scores similar to those of adult males without a disability, mirroring results from the earlier study. Adult females with cerebral palsy (mean age 22.8 years) reported an improvement in their self-esteem since entering adulthood, and while self-esteem scores were still lower than the other groups, they weren't significantly so. The most important factors in maintaining and improving self-esteem were much the same for all participants alike—participating in a range of experiences and having supportive relationships.

For adults with cerebral palsy, access to social support has a particularly positive effect on self-esteem (Magill-Evans & Restall 1991). For those who do not have that access, or experience restricted access, self-esteem may be compromised and loneliness and isolation felt. Balandin and colleagues (2006) asked Australian adults aged 40 years and over and with cerebral palsy to record their level of loneliness (using the University of California Los Angeles Loneliness Scale (Version 3)). It was found to be much more pronounced compared with similarly aged adults without a disability. The majority of the study group lived in a group or nursing home, which was considered to impact even more acutely on their feelings of loneliness by denying regular contact with family and friends and restricting their ability to meet new people, make new friends and maintain other relationships. Issues of restricted mobility, access to transport and ability to preserve independence were other cited factors.

The process of ageing among people with cerebral palsy has also received scant research attention. An Australian study on the health of adults with cerebral palsy and their contact with health services found over three quarters of participants were experiencing a change in their physical condition; only 4% of these people described this change as positive (Balandin & Morgan 1997). These physical changes affected a range of body structures and functions but most commonly affected the back, legs, neck, arms and hips (between 24–29% of respondents), and mostly altered their ability to walk (29%). Emotional changes were also experienced, particularly increased frustration, fatigue and pain. Over a quarter (27%) of the adults with cerebral palsy surveyed felt these physical and emotional changes had affected their independence and life style. Similar experiences were expressed by adults with cerebral palsy aged 23–82 years and resident in the UK—walking became more difficult once they entered middle age, which subsequently impacted on their mobility and ability to participate, and caused increased anxiety and depression (Willner & Dunning 1993).

Use of services

The literature on service use among adults of cerebral palsy tends to focus on the use of health care services (such as general practitioners). For Australia, this literature considers the general population with cerebral palsy, with little investigation into service use by Aboriginal and Torres Strait Islanders peoples or persons from a non-English speaking background.

Murphy et al. (1995) reported a general lack of preventative medical care being available to adults with cerebral palsy in the US, with 90% of adults in their study not having periodic general health evaluations. In contrast, most adults with cerebral palsy in Australia and the UK surveyed by Balandin and Morgan (1997) and Willner and Dunning (1993), respectively, did report visiting their doctor at least yearly, with over 50% making the visit every 6 months or more frequently. Around 74% of the Australian adults felt their general practitioner knew them well. One concern, however, expressed by some of the Australian adults was physical access issues, such as difficulty accessing examination facilities.

Successful and appropriate medical care may be hampered if communication difficulties exist, the medical practitioner has limited knowledge about the condition (Rapp & Torres 2000), or there are potential negative attitudes towards treating a person with cerebral palsy (Martin et al. 2005). While more than half of the Australian adults surveyed in Balandin and Morgan's (1997) study were happy with the information they received from their general practitioner, and felt their general practitioner was interested in what they had to say, 42% still suspected their general practitioner did not have a lot of knowledge about cerebral palsy.

The transition to adulthood may be accompanied by a change or unplanned decline in therapeutic contact. Twenty-one of 36 carers caring for an adult with cerebral palsy in the

UK ranked physiotherapy as the most important service, ahead of regular general practitioner check-ups, speech pathology and occupational therapy (Stevenson et al. 1997). However, only 10 of the 42 adults questioned about their contact with services reported at least one contact with a physiotherapist in the last 12 months. Adults with cerebral palsy in Italy were also frustrated by a lack of therapeutic contact. While six had never received therapy, 37 did receive therapy in their teenage years, mostly from physiotherapists, but experienced a markedly reduced frequency in therapy services once they turned 18 (Bottos et al. 2001). Therapy did continue more or less as before for the remaining 23 adults. The continuity of therapy was better for younger adults than for older adults.

Respondents in the Australian study were asked to list the therapy (and other health) professionals they had visited in the last 12 months—48% had seen a physiotherapist, 41% an occupational therapist, 28% a speech pathologist and 16% a psychologist (Balandin & Morgan 1997). No information was collected on the (additional) proportion of respondents needing to visit one of these professionals but unable to do so.

For people living in remote communities in Australia, access to medical and allied health services is generally limited. Numbers of allied health professionals per 100,000 population are much lower in very remote areas than in capital cities—for example, 64 physiotherapists per 100,000 population in capital cities compared with just 14 per 100,000 in very remote areas (Ramsay et al. 2005).

Several studies have examined current patterns of service provision in remote areas. The Central Australian Allied Health Planning Study determined, using a series of benchmarks for allied health disciplines, that 58.15 full-time-equivalent (FTE) allied health professionals are required to adequately service communities (Ramsay et al. 2005). In 2004, there were 26.25 FTE professionals working in the study area. This shortfall of 31.9 FTEs included a shortfall of 3.2 occupational therapists, 3.3 physiotherapists and 4.8 speech pathologists.

Another study, focusing on 11 remote communities (Indigenous, non-Indigenous, and mixed) in north-west Queensland, revealed that no occupational therapist or speech pathologist services were available to adults, and physiotherapy, dietetics, podiatry and psychology services were provided by visiting professionals on an irregular basis, depending on the availability of staff at base locations (Battye & McTaggart 2003). Community consultation raised a number of concerns about the adequacy of allied health services available to the communities, and these included:

- problems with frequency of service, and visits to communities being too short
- lack of consistency of service provision, and high staff turnover
- lack of provision of some disciplines for adults
- insufficient notice about when services were coming to a community, problems with referral mechanisms, and inadequate promotion of visiting services
- poor coordination among visiting services
- inadequate cultural awareness and language/communication issues.

3.4 The nature of therapy

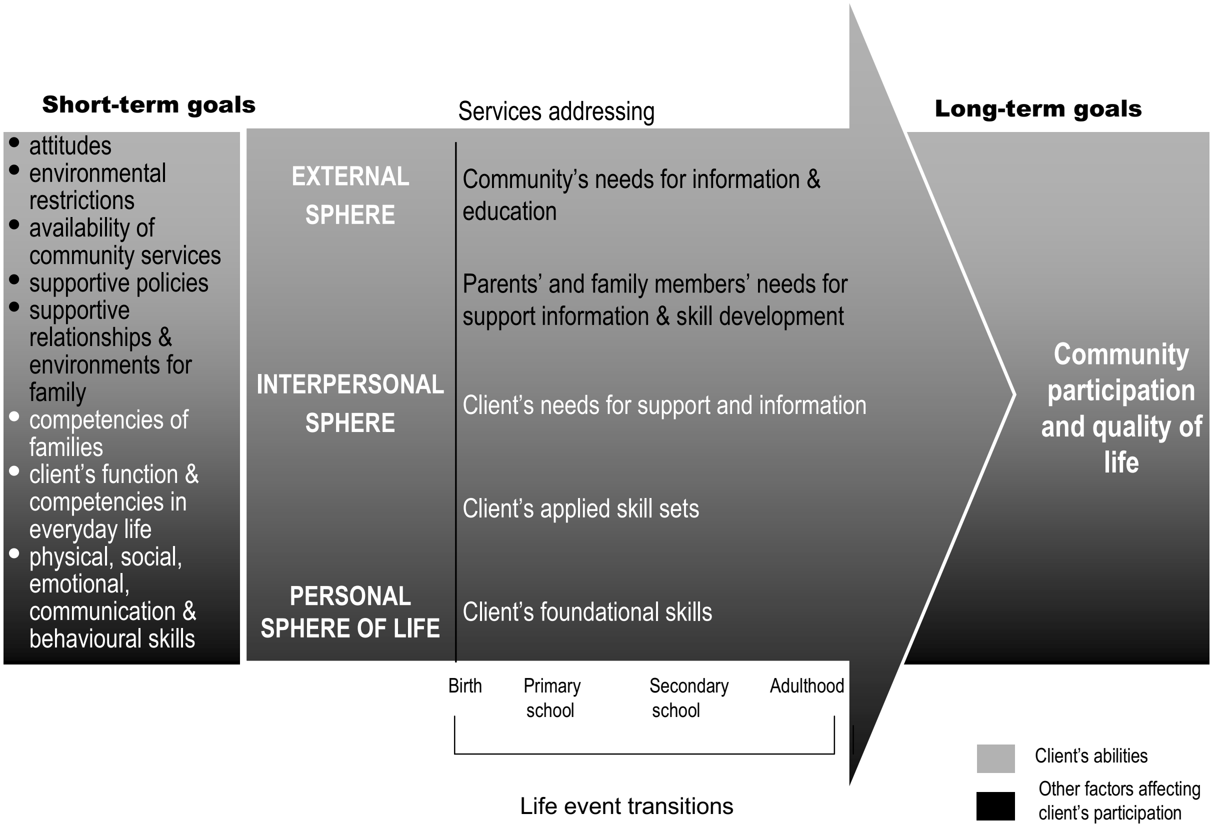
The way in which health care, including therapy, is provided to people with cerebral palsy has changed over time, paralleling changes in community attitudes about disability. There has been a shift away from focussing on trying to cure or normalise impairments, to considering the person's needs within the context of their daily activities and routines and also their participation in family and community life (Krigger 2006; Palisano et al. 2004). Goal setting is the main strategy currently used to develop intervention programs for people with cerebral palsy (Green et al. 1997), because personal goals provide a direct reflection of the individual's needs (Koman et al. 2004). The goals developed need to be realistic and yet sufficiently challenging to allow the person to reach their full potential (Green et al. 1997). To meet these goals and achieve optimal outcomes a range of health professions is needed, with one of the key groups being 'therapists' (Krigger 2006). This section will define therapy and describe the types, roles and responsibilities of professionals usually involved in providing therapy to persons with cerebral palsy.

What is therapy?

Therapy aims to develop, improve, and/or maintain the well-being and participation of an individual in society. Therapy may be regarded as the range of interventions performed or prescribed for the purpose of reaching individualised goals, irrespective of the professional who performs or prescribes them. The Cerebral Palsy Association of Western Australia defines therapy as,

> any intervention performed or prescribed by a therapist that promotes independence, improves functional ability and minimises the impact of disability (Cerebral Palsy Association of Western Australia (CPAWA) 1997).

For people with disabilities, therapy can be a fluid process that evolves and changes according to the needs of the individual across the lifespan. The current understanding of therapy and its impact on a person with a disability is summarised in the Life Needs Model (Figure 3.1).



Source: King et al. 2002

Figure 3.1: Life needs model

This model recognises that the outcomes of therapy are affected by the client (personal sphere), the family (inter-personal sphere) and the community (external sphere). It also recognises that any therapeutic approach must consider changes in the need for and receipt of therapy over an individual's life, including the type and intensity of therapy, and the episodic nature of therapy provision (Bottos et al. 2001; Palisano et al. 2004). Former approaches sought to intervene solely at the impairment level focussing exclusively on the personal sphere. More recently, therapy has broadened its focus to include the family and community. This emphasis is evident in the diverse group of professionals involved in therapy and the types of therapy they provide (see next section on specific professional disciplines).

Definitions of therapy vary, influenced in part by the client group, therapist,[4] intervention, and therapeutic setting to which they relate. Therapy can also be described according to the approaches and philosophies that structure its delivery. As a consequence, the boundaries of therapy often overlap between professions. In order to sketch some of these boundaries,

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[4] Therapist, rather than clinician, will be used in this section. This term acknowledges that therapy can be provided by a diverse group of people, who may or may not be professionally trained in a health discipline.

definitions of therapy will be explored in relation to specific professional disciplines, multiple disciplines and the person or client receiving the services.

To narrow the scope of the project, interventions that aim to change impairment and are undertaken by the medical profession are excluded. These interventions include orthopaedic surgery or neurosurgery, such as selective dorsal rhizotomy, or pharmacological medical treatments aimed at body functions or structures, such as botulinum toxin A or intrathecal baclofen pumps.

Specific professional disciplines

Professionals involved in a person's health care will:

> depend on the individual…and family situation, but may include a primary physician, physician specialists (neurology, physiatry, orthopedics, neurosurgery, etc.), therapists (physical, occupational, speech, recreational, etc.), orthotist, nurse, psychologist, social worker etc (Delgado & Coombes 1999:42).

While medical and surgical management is common for people with cerebral palsy, it is usually accompanied by therapy including physiotherapy, occupational therapy and speech pathology (Koman et al. 2004). In the Australian context, the description of a therapist is a professional trained in one of these three disciplines as well as social work or clinical psychology, and the scope of therapy could be confined to interventions provided by this core selection of therapists (CPAWA 1997). Each profession is described below by standard definitions from Australian professional organisations.

Physiotherapy

'Physiotherapy is a health profession concerned with maximising mobility and quality of life by using clinical reasoning to select and apply the appropriate treatment' (Australian Physiotherapy Association 2006). In the management of cerebral palsy, physiotherapy is concerned primarily with improving and maintaining the person's movement skills (Green et al. 1997). Together with occupational therapists, physiotherapists use device assisted modalities such as electrical stimulation, strength training, stretching, specialist equipment such as walking aides and specialist seating, orthotics, and casting (Chen et al. 2004). Physiotherapists also play a role in supporting and improving the general health and well being of clients and their families.

Occupational therapy

Occupational therapists aim 'to assist each individual to move from dependence to independence, maximising personal productivity, well-being and quality of life' (Australian Association of Occupational Therapists 2006), which is likely to involve addressing arm use and self-care skills (Green et al. 1997).

Occupational therapy work can involve:

- assisting in activities of self-care (for example, dressing), play and fine motor tasks (for example, writing)
- addressing cognitive and perceptual impairments
- adapting aids and equipment

- environmental assessment and adaptation
- parental counselling
- developing independence for living and social participation (Steultjens et al. 2004).

Speech pathology

Speech pathologists (also known as speech therapists or speech-language pathologists) are involved in the assessment, diagnosis and treatment of communication disorders. The aim of speech therapy is to maximise a person's ability to 'communicate through speech, gesture and/or supplementary means such as communication aids, to enable them to be independent communicators' (Pennington et al. 2003). Speech pathologists also work with people who have difficulties swallowing food and drink.

Speech therapy intervention can focus on:

- speech (for example, the formation of sounds and words)
- expressive or receptive language development
- conversation skills (including the training of conversation partners) (Pennington et al. 2005)
- swallowing difficulties (Hemsley & Balandin 2003).

The use of aids and equipment, such as symbol cards or speech synthesizers, is common in speech therapy services.

Psychology

Psychologists work with 'mentally healthy[5] people to assist them to function better' (Australian Psychological Association 2006). There are many components of a psychologist's work including specialised psychological assessment, counselling (including grief and cognitive behavioural), facilitation of support/network groups and the provision of advice and education. Psychologists are usually a first contact for families after initial diagnosis.

In the management of cerebral palsy, psychologists may provide assistance to clients and/or families on a range of issues such as living with a disability, key life transitions, social and anxiety issues, parenting and behaviour management. In addition, psychologists also provide specialist assessment of intellect and learning abilities. This assessment is important for understanding a person's academic and work potential as well as their likelihood of independence in adulthood.

Social work

'Social work is the profession committed to the pursuit of social justice, to the enhancement of the quality of life and the development of the full potential of each individual, group and community in society' (Australian Association of Social Workers 2006).

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[5] Mentally healthy people do not have a mental illness. While there is considerable overlap in the role of psychologists and psychiatrists, psychiatrists mainly treat people with a mental illness, such as schizophrenia.

In the management of people with disabilities, key components of social work include:

- advocacy for people and families living with a disability
- addressing barriers and inequities that exist in society (for example, access to community buildings)
- providing personal support during times of distress or transition (for example, important life transitions) (Bridge 1999).

This means that social workers are also a key first contact for families after initial diagnosis.

The family support provided by social workers and psychologists are principally aimed at improving family functioning, via techniques such as mutual aid support groups, empowerment and behaviour management (Dabney et al. 1997). Many of these interventions are preventative in nature, designed to strengthen family coping and keep families together.

These five professions work together in teams (and with other professionals such as orthopaedic and medical specialists and educators) to deliver the most effective and comprehensive health care interventions (Wagner 2000). The teams provide continuous health care involving: identifying problems and needs of individuals; relating the problems to personal and environmental factors; defining therapy goals; planning and implementing the interventions; and finally measuring the effects of interventions (Steiner et al. 2002).

Multiple disciplines and beyond

Often the boundaries between professions are unclear and there is considerable overlap and sharing of responsibilities (Hinchcliffe 2003; Michaud 2004). Increasingly, transdisciplinary approaches are being used for people with cerebral palsy and like disabilities—that is, professionals with different clinical backgrounds work collaboratively to deliver interventions that cut across the traditional boundaries of different clinical disciplines. Labour force challenges relating to recruitment and retention of staff may also widen and redefine the roles and responsibilities of therapists (Smith et al. 2000), particularly in rural and remote areas where there is a particular undersupply of allied health personnel (Millsteed 2000; Morris & Palmer 1994).

As cerebral palsy has multiple clinical features affecting numerous body systems, it is likely that different therapies will be sought. Siebes et al. (2002) found great variability in therapies for children with cerebral palsy. Interventions in other allied health areas (such as orthotics, dietetics and recreation specialists) are common, useful and often part of a multidisciplinary approach to care (Cooley 2004).

Complementary and alternative therapies (such as acupuncture) and recreational therapy (involving sports, arts and music) are also used in the management of cerebral palsy (Liptak 2005). In some cases there may be no clinicians involved and interventions across all areas may be done by rehabilitation assistants, teachers, family members, carers or anyone who has the interest and ability to learn the skills (Macvean & Hall 1997), although there is often some initial clinician involvement to teach carers how to continue therapy day to day. This is often the case as therapy services are applied across a number of different settings, for example community centre, play group, schools and the home (Australian Capital Territory Department of Disability, Housing and Community Services (ACT DDHCS) 2005; Law et al. 2003).

Roles and responsibilities of therapists

The nature of therapy varies depending on the needs of the person, their family, the community and the resources available. The diverse roles and responsibilities of therapists in the management of cerebral palsy are summarised below (ACT DDHCS 2005; CPAWA 1997; Dunn 2000a; Murchland 2003; SCOPE 2006). Additional professional roles and responsibilities related to management, research and/or business development are not included here.

The roles and responsibilities of a therapist are to:

- participate in the decision making process regarding client's and families goals/needs
- assess client needs and abilities within context of family and environmental factors
- conduct and evaluate direct clinical interventions (for example massage, stretching and counselling)
- participate in individualised program planning (for example Individualised Education Programme)
- screen and assess client environments (for example school or workplace)
- liaise and negotiate with other care providers across multiple sectors (education health, and community services)
- assess, prescribe, order, maintain and evaluate aids and equipment
- provide information and education to clients, families, caregivers and wider public (for example, information on available services and back care management)
- advocate for the client and family ensuring culturally sensitive practices are adhered to where appropriate
- maintain client record and information requirements.

Therapy through team work

Professionals providing services to people with cerebral palsy work together in teams, because it is understood that teams deliver the most effective and comprehensive services (Wagner 2000). These teams include the person and their family as equal members (Viscardis 1998). There are different approaches to the way teams operate, with the three principal approaches being multidisciplinary, interdisciplinary and transdisciplinary (Dunn 2000a). These three approaches principally differ by the degree of involvement each discipline has in the therapeutic process.

- A **multidisciplinary approach** includes various professions in the team where the various therapeutic interventions are provided in isolation and the professions 'co-exist' (Dunn 2000a). This approach recognises the importance of different disciplines in the therapeutic process and involves professionals operating within the boundaries of their profession towards discipline-specific goals while recognising the importance and contribution from other disciplines.
- An **interdisciplinary approach** involves professionals working towards shared goals and implementation plans, but implementing their own sections of the plan independently (Australian Capital Territory Department of Disability, Housing and Community Services 2005). The team members negotiate about priorities and the plan implemented reflects the group consensus (Dunn 2000a).

- A **transdisciplinary approach** is one where the team members work together throughout the service planning and implementation phases. The unique feature of this approach is that team members determine who is the most suitable professional to implement the services and therefore who acts on behalf of the team (Dunn 2000a). Each profession contributes to the assessment and goal-setting process but one professional implements the program (Dunn 2000a).

In Australia, services for people with cerebral palsy are provided within an interdisciplinary or transdisciplinary approach. The underpinning belief about teamwork is that when professionals from diverse backgrounds work together, they benefit from the range of expertise, which enhances the service plan and builds team ownership and commitment towards the mutually agreed goals (Maher & Bennett 1984).

Goals provide the basis for the development of individualised therapy plans (or service plans), as interventions are more useful when directed towards functional and realistic goals (Bottos & Gericke 2003; Ketelaar et al. 2001). Goals can also provide a consistent link between services which ensures harmonisation between service providers (Ahl et al. 2005). These service plans are developed by the team in consultation with the person and/or their family, and outline the desired outcomes of intervention, who is responsible and the proposed timeline (Dunn 2000b). 'Individual Family Service Plan(s)' and 'Individual Education Plan(s)', both specific to children, are two examples of service plans widely used in Australia.

Teams adopt different service delivery styles. The ways in which therapists use their time to provide services are known as models of service provision (Dunn 2000b). A continuum of therapy service delivery options exist, which include direct service, supervised therapy, and consultation. This continuum is designed to be responsive to individual and families needs by considering the variety of environments in which intervention may occur, the person's individual needs, and, for children, the skills and preferences of a child's parents and significant others (Dunn 2000b).

- **Direct therapy.** Direct therapy is when the therapist designs and carries out intervention with a person individually or in small groups (Dunn 2000b). Direct therapy is indicated when the intervention cannot be carried out by others in the person's life because of the specialist technique being used or for safety reasons (Dunn 2000b). Direct therapy is never used in isolation within best practice, rather it is used in combination with other service models to ensure generalisation of skills within natural settings (Dunn 2000b).
- **Supervised therapy**. Supervised therapy or integrated therapy is where the therapist supports a person's outcomes via secondary service provision (Dunn 2000b), and is therefore generally more applicable to children where it is often utilised in inclusive school settings. In supervised therapy, the therapist conducts an assessment and designs an individualised intervention program; they then train another individual within the person's natural environment to carry out the plan (Dunn 2000b). The aim is to make daily life more therapeutic (Dunn 2000b). The therapist remains in regular contact and monitors progress through identifying when the plan needs adjustment (Dunn 2000b).
- **Consultation.** In the consultation model, the therapist is not responsible for a person's outcome but rather the collaborative efforts with a parent or carer who is carrying out the program (Dunn 2000b). There are three types of consultation: (1) case consultation where the therapist consults with another care provider to provide solutions for the person receiving therapy; (2) colleague consultation where the therapist consults to provide solutions for another care provider on a general level; and (3) system

consultation or population-based services focuses on achieving improvements within the system the intervention is being provided (Dunn 2000b).

Changes in the needs of persons with cerebral palsy, health care services, funding and practice models have all influenced the way in which therapy services are now provided to people with disabilities (Jirikowic et al 2001). To respond to these changes therapists currently supplement direct services with consultation and monitoring (Jirikowic et al. 2001; McEwen & Sheldon 1995).

3.5 Frameworks for and approaches to therapy

Current best practice therapy for people with cerebral palsy emphasises the following features of care (CPAWA 2005a):

- inclusion and participation in major life areas across the life cycle (Rosenbaum & Stewart 2004)
- family centred-practice for children and families and client-centred practice for youth and adults
- a transdisciplinary team approach to service delivery that recognises the individual and complementary value of team members
- a functional and an ecological approach acknowledging the importance of learning meaningful tasks in everyday environments (see, for example, Ahl et al. 2005; Ketelaar et al. 2001)
- accountability to the client and families as client satisfaction provides an indication of therapy outcomes (King et al. 2002)
- professional standards and ethical and culturally sensitive principles.

The philosophies and frameworks of these guiding principles are described in more detail below.

Therapy to enhance participation

The ICF provides a multidimensional framework for defining functioning and disability. As therapeutic interventions for cerebral palsy focus less on treatment of a 'cause' and more on the spectrum of disability (Shevell & Bodensteiner 2004), the ICF provides a sound framework for considering therapy and is being increasingly applied in related research. The dynamic and multidimensional nature of the ICF obliges therapy services to view disability (and the planning of therapeutic interventions) in a variety of different contexts (that is, across the spectrum of a person's lived environment) and with a focus on decreasing limitations and maximising participation. As an individual's functioning, activity performance and participation needs change with age, the ICF also provides a framework for appropriate service planning and delivery throughout the lifespan. The 'participation' domain of the ICF is receiving increasing attention in the area of cerebral palsy therapy research. Indeed it is recognised that one of the primary goals of therapy intervention for children with disabilities is enabling participation in the daily activities of childhood (Law et al. 2004). Expert cerebral palsy researchers have called for a move beyond diagnosis to focus on other personal and environmental factors as major predictors of participation (Law et al. 2004). This is because participation is a complex phenomenon influenced by personal, environmental and family factors that all affect a person's involvement in everyday activities (Law et al. 2004).

The environment is a critical component of the ICF and environmental factors affect the delivery of therapy. This area of the ICF will be discussed in depth in the ecological approach to therapy. Personal factors, which include basic demographics (for example age and sex), sociocultural characteristics (such as indigenous status) and income status are recognised in the ICF (but not classified), and can also affect decisions about the timing and type of therapeutic intervention (Tilton 2004).

Rosenbaum and Stewart (2004) acknowledge the important role the ICF can play in the planning of interventions which promote well being and advocate use of the ICF in future cerebral palsy research. The ICF framework has already been applied in some studies of cerebral palsy. Morris et al. (2005) recognise the importance of measuring activity performance and participation in generic health-related quality of life assessment instruments, and cerebral palsy research considering the relationship between impairments, activity performance and participation in life domains (for example mobility) is emerging (Beckung & Hagberg 2002; Schenker et al. 2005a; 2005b).

Therapy underpinned by family-centred practice

Family centred practice is an approach that

> begins with the child's and family's strengths, needs and hopes, and results in a service plan which responds to the needs of the whole family. It involves education, support, direct services and self-help approaches. The role of the service provider is to support, encourage and enhance the competence of parents in their role as caregivers (Viscardis 1998:44).

Central to the idea of family-centred care is the belief that families know and are able to make decisions concerning the welfare of their child with a disability. Parents are able to work as partners with professionals and have the right and responsibility to be so involved with their child (Viscardis 1998). Key elements of family-centred practice are:

- recognising that the family is the constant in a child's life, while the service systems and personnel within those systems fluctuate
- facilitating the collaboration between the parent and professional at all levels of health care, from the care of an individual child to policy development
- honouring the racial, ethnic, cultural and socio-economic diversity of families
- recognising family strengths and individuality and respecting different methods of coping
- sharing with parents complete and unbiased information on a continuing basis and in a supportive manner
- encouraging and facilitating family-to-family support and networking
- understanding and incorporating the developmental needs of infants, children, adolescents and their families into health care systems
- implementing comprehensive policies and programs that provide emotional and financial support to meet the needs of families

- designing accessible health care systems that are flexible, culturally competent and responsive to family identified needs (National Centre for Family-Centred Care 1990)..

The family-centred approach is a major change from the 'medical model' where, traditionally, the child was the primary focus of intervention and the expert professional was central to decision making (Bailey et al. 1992; Dormans & Pellegrino 1998; Dunst 1991; King et al. 1998; Leviton et al. 1992; Rosenbaum et al. 1998; Winton & Bailey 1997). In the family-centred approach the professional's role has changed to become the provider of a service that meets the needs identified by families (Viscardis 1998). For children with cerebral palsy, therapy provided from the family-centred approach is aimed at assisting parents to build a repertoire of skills that enhance their interaction with their children and structuring the environment to enhance the child's development (Washington & Schwartz 1996).

The outcomes of using the family-centred approach are that:

- collaborative goal setting better addresses families' most important needs
- jointly developed action plans improve the likelihood that desired outcomes are achieved
- good working relationships between professionals and families enable better use of services
- supporting family decision-making builds family confidence, competence and the family's ability to make decisions over their child's lifetime
- sharing and respecting mutual knowledge and expertise leads to better solutions for the child and family
- building a family-based support structure reduces dependency on professionals (Moore 2004).

Benefits of family-centred practices are reported to be (Rosenbaum et al. 1998):

- increased parent participation in intervention (Moxley-Haegert & Serbin 1983)
- greater parental acquisition of health knowledge (Moxley-Haegert & Serbin 1983)
- greater achievement of motor and developmental skills by children (Moxley-Haegert & Serbin 1983; Parker et al. 1992)
- greater parental satisfaction (Davis & Gettinger 1995; Stein & Jessop 1984)
- better psychological adjustment in the child (Pless et al. 1994; Stein & Jessop 1984).

Family-centred practice, by means of team collaboration, is recognised as the gold standard in service provision for children with cerebral palsy (Dormans & Pellegrino 1998) and has been adopted in Australia as best practice (Hanna & Rodger 2002; New South Wales Department of Community Services 1993).

Therapy guided by a functional and ecological approach

The functional approach to intervention is where functional skills are practiced to achieve functional goals (Ahl et al. 2005). The formulation of specific goals which are meaningful to the client is critical for therapy to be functional in nature (Ahl et al. 2005; Ketelaar et al. 2001). Central to this approach is that tasks and skills under development are meaningful to the person and the important others in their lives (Law et al. 1998). Through the use of internally motivating activities the person becomes an active problem solver in their own therapy rather than a passive recipient (Ahl et al. 2005).

The ecological approach to therapy intervention places emphasis on people learning in real life contexts, rather than in intervention settings (Ahl et al. 2005). Therapy provided from an ecological approach recognises the complex interaction between the individual with cerebral palsy, the task they are trying to achieve and the environment in which they are learning (Ahl et al. 2005). This premise is built upon the understanding that learning can be influenced by: (1) person-specific constraints, due to the person's physical, psychosocial and intellectual abilities; (2) task constraints, arising from equipment and task restrictions that limit the person's ability to perform; and (3) environmental constraints, such as physical, social and cultural factors (Law et al. 1998). Therapy can therefore be carried out in a range of environments, and are increasingly being used in the home environment (Ellis & Logan 2001; Piggot et al. 2002).

For children, a parent's approach and style is a key element of the environmental impact on a child's learning (Law et al. 1998). Collaboration with parents is therefore essential to providing effective therapy in natural environments. When achieved in paediatric services it produces enhanced family and parent-therapist relationships, enhanced parental caregiving competency and improved capacity to assess a child's strengths and select meaningful outcomes (Hanft & Pilkington 2000).

The functional and ecological approach work in combination, as the ecological approach extends the functional approach by specifying that functional training should happen in an every day context. The idea behind the approach is that task practice in natural settings will promote skill generalisation because natural settings provide all the extraneous factors that arise in everyday contexts (Law et al. 1998).

The functional and ecological approach is also routinely coupled with family-centred practice when providing therapy to children with cerebral palsy. Indeed working within natural environments is considered an extension of family-centred care (Hanft & Pilkington 2000). This combined approach to therapy provision has been named 'family-centred functional therapy' (Law et al. 1998).

There is increasing literature on the effects of environmental factors on functioning and participation of people with cerebral palsy (Hammal et al. 2004; Mihaylov et al. 2004; Østenjø et al. 2003; Palisano et al. 2003; Simeonsson et al. 2001; Tieman et al. 2004). These include physical factors such as accessible buildings and aids and equipment, as well as the partnership and attitudes of caregivers, family members and peers. The environment is also considered an important factor in the formulation and achievement of therapy goals (Darrah et al. 2001), and so environmental constraints and facilitators should be identified in therapy plans and interventions.

Consideration of environmental facilitators and barriers underpins the five ecological approaches of therapy provision first described by Dunn et al. (1994).

- **Establish/ restore** therapies are treatments that establish or restore a person's abilities to perform in a context. It involves identifying the person's skills and barriers to performance and designing interventions that improve the person's skills (Dunn 2000b). Establish/restore interventions address a person's body structures and functions, and hence their ability to undertake activities, that affect their difficulty in achieving a specified goal. This type of intervention is what is classically thought of as 'hands on' therapy.
- **Adapt/ modify** therapies adapt contextual features and task demands so they are more supportive of the person's performance, so performance is more possible (Dunn 2000b).

Adapt/modify interventions address any 'task variables' that are barriers preventing the person achieving their goal. In the ICF framework, 'adapt' interventions can be thought of as intervening at the environmental level.

- **Alter** interventions alter the context within which the person performs. This type of therapy emphasises selecting an environmental context that enables the person to perform with their current abilities. It can also include repositioning a person into a different setting that better matches their ability level (Dunn 2000b). Alter interventions address environmental barriers preventing the person achieving their goal.
- **Prevent** interventions are therapies that prevent the development of barriers to performance. At times therapists can predict that certain unwanted outcomes are likely without therapeutic interventions. Therapists then create interventions to change the sequelae of events, by addressing personal factors, impairments at the body structure level and environmental barriers.
- **Create** interventions focus on creating an environment suitable for all, without a specific focus on a person with a disability (Dunn 2000b).

3.6 Therapy across the lifespan

It is important that therapy services support the inclusion and participation of clients throughout the lifespan and take into consideration the age of the client and the life transitions they will encounter, because as a person with cerebral palsy grows older their therapy needs and goals will change (Jahnsen et al. 2003; Mullens 2002). For example, in the early years therapy concentrates on minimising impairment and enhancing motor development, in school ages on adaptive and integrative goals, and in older age groups on community integration, the effects of ageing and associated comorbidities.

To capture key transitional life stages, such as the commencement of school, adolescence, and adulthood, the therapy needs and goals of people with cerebral palsy aged 0–5, 6–17 and 18–65 years are discussed in turn.

0–5 years: Early childhood

Early childhood is regarded as a critical time for developing physical, cognitive, emotional and social skills that form the foundations of lifelong healthy development (Park & Peterson 2003). The goals of therapy in this life stage focus on enhancing development and minimising impairment by preventing muscle contractures and muscle deterioration caused from a lack of use.

Therapy usually begins in the first few years of life, shortly after a diagnosis of cerebral palsy is made, so as to ensure the child develops, enhances and maintains skills (CPAWA 2005b). Early intervention programs consist of multidisciplinary services provided during early childhood 'to promote health and wellbeing, enhance emerging competencies, minimise developmental delays, remediate existing or emerging disabilities, prevent functional deterioration, and promote adaptive parenting and overall family functioning' (Blauw-Hospers & Hadders-Algra 2005:421).

Therapists focus on promoting the child's skill acquisition, adapting the environment and the task so as to be more conducive to participation, and eliminating restrictions experienced by the child and family (Lammi & Law 2003). Therapy in early childhood is delivered in the home, in early intervention groups or in preschool and, wherever possible, is integrated into the child's daily routines.

Generally, early intervention programs use techniques derived from physiotherapy, occupational therapy, developmental psychology, social work and speech pathology (CPAWA 2005b). There is often considerable overlap and sharing of responsibilities among therapists.

Areas in which therapists may aid in early intervention include skill development, social and emotional development, family and carer support, parent education and counselling, equipment and funding applications, therapy training for family members, information on leisure and recreation, links with other services, and preparation for and support to preschools and childcare centres.

6–17 years: School age

As the child with cerebral palsy approaches school age, the emphasis of therapy shifts to promoting independence by preparing the child for school and helping them to access their classroom, curriculum and extra-curricular activities, and master activities of daily living such as dressing, bathing, and eating. Therapy may be delivered in school, the home, or at after school or holiday programs.

The inclusion of children with disabilities in mainstream education is a generally accepted policy in the Australian school system (AIHW 2005). Thus, increasing numbers of children with cerebral palsy attend mainstream schools and are expected to complete classroom activities and participate in school life (Schenker et al. 2005a). Therapists work with children, their families and school to help the child with cerebral palsy access and maximise their participation in the classroom and become more autonomous in activities of daily living.

Physiotherapists can help the child with cerebral palsy prepare for the classroom by improving their ability to sit, move independently or in a wheelchair, and perform precise tasks, such as writing.

Occupational therapists may work with the child to develop fine motor tasks such as writing and drawing, self-care activities such as eating, dressing, grooming and toileting, and play and social skills, which can help reduce demands on teacher aids and caregivers and boost the child's independence and self-esteem. Occupational therapists may also assist with the adaptation of equipment, such as seating, or appropriate technology to allow enhanced participation at school. Additionally, occupational therapists may be involved with developing organisational skills related to planning, initiating, completing and modifying tasks to ensure and enable completion of routines and problem-solving associated with new activities.

Speech therapists may assist with speech, language, conversation and swallowing skills by identifying specific difficulties and overcoming them through exercises or modifying the environment or situations. Speech therapists can also recommend suitable communication devices and help the child learn to use the special equipment.

Therapists of all types may also set up programs for teachers' aides to implement in the classroom to make sure the child can move around safely in the school environment, recommend changes of seating positions for parts of the day, provide ideas about modifying activities to help the child complete them successfully, recommend suitable equipment, and instruct on the use of computers, keyboards and software to help with learning in the classroom.

Therapists also see young people outside school hours. Individual sessions may be set up to work on developing a new skill, conduct assessments, prescribe appropriate equipment or review existing equipment, recommend activities for home and provide practical ideas about modifying the home. Therapists may also be involved in finding respite and recreational activities and helping with funding submissions.

Adolescence deserves particular mention. Adolescence is the transitional period of significant physical, emotional and social change between childhood and adulthood (Magill-Evans et al. 2001). In adolescence, therapy needs go beyond the consideration of aids and equipment and activities of daily living into issues of identity, independence, employment, living arrangements and the development of social and intimate relationships (Ko & McEnery 2004) (see the following section on adulthood for further discussion of therapy focussing on these issues).

Counselling for emotional and psychological challenges may be needed at any age but is often most critical during adolescence. Social workers can also provide emotional support to families during stressful times and can play a part in helping plan for the future.

Young people with cerebral palsy also face the challenge of staying independently mobile as they begin to experience the rapid physical growth that is associated with puberty. The effects of growth predispose young people with cerebral palsy to the problems of muscle contractures, in which muscles become fixed in a rigid, abnormal position, as well as bony deformities and gait abnormalities (Morris 2002). Physiotherapy works to slow or prevent these complications and is also important in post-surgical rehabilitation.

18–65 years: Adulthood

As the young person with cerebral palsy makes their transition to adult life, the emphasis of therapy turns to assisting and supporting independence and promoting social participation and full community integration. Therapists provide services to adults with cerebral palsy that focus on the acquisition, development and maintenance of skills, the promotion of functional independence, encouragement of community integration and participation, and assistance to live independently in the community (CPAWA 2005c).

Therapy in adulthood also focuses on managing the effects of ageing and associated comorbidities. People with cerebral palsy generally notice the effects of ageing at an earlier age, with a more rapid decline in function than in people without a disability (Majnemer & Mazar 2004; Sandstrom et al. 2004; Zaffuto-Sforza 2005). Problems reported by adults include fractures due to osteoporosis and increased falls, urinary problems, psychological problems, fatigue, musculoskeletal deformities, overuse syndromes, low levels of physical fitness and pain (Palisano et al. 2004).

Physiotherapists work to maintain their clients' optimal mobility, to enable them to become and to remain as independent as possible. They are also involved in preventative activity programs and post-surgical rehabilitation. Speech pathologists promote the development of communication, and assist with mealtime management. Occupational therapists are involved in the prescription and assessment of equipment, the adaptation of work/leisure environments, home modifications and activities of daily living. Social workers support adults to develop their social, emotional and personal wellbeing. They work with people in areas such as linking individuals with appropriate resources to enhance independence (for example, funding, accommodation, respite and employment), counselling (for example, grief, life stage issues and crisis), stress management, personal development and future planning.

3.7 Effectiveness of therapy

Since therapy is considered to be an important part of the management of cerebral palsy, it is important for therapists to know about the effectiveness of treatment techniques. This assists therapists to make informed decisions about patient care and allocate limited therapy resources to achieve the best outcomes for people with cerebral palsy, their families and the wider community (Dodd et al. 2002).

Before a method can be deemed effective, positive change must be evident for the person with cerebral palsy or their caregiver. There may be change at the functional level, such as increased participation in home and community activities or improved ability to perform tasks, or therapy may help prevent the development of secondary deformities or pain (Stanger & Oresic 2003). These effects can be measured using a range of outcome measures.

Outcome measures

Outcome measures are used to confirm the changes or progress made when evaluating the effectiveness of therapy. Outcomes are usually defined as the extent to which goals are achieved (Tennant 2000). Outcome measures also help to specify whether a change is occurring at the body structures level or at an activity or participation limitation level (Majnemer & Mazar 2004).

Traditionally, therapy interventions have largely focussed on minimising impairments such as decreasing spasticity and reducing contractures, in the hope of promoting more ‘normal’ movement patterns (Majnemer & Mazar 2004). In more recent years therapists have begun to broaden their intervention goals to include all areas of functioning as defined in the ICF. To reflect this broader approach, it is recommended that outcome measures evaluate outcomes at the level of the organ system (body functions and body structures), as well as at individual (activity) and societal (participation) levels (Majnemer & Mazar 2004). Additionally, to ensure a more complete description of functioning, it is recommended that multiple outcome measures are used (Stanger & Oresic 2003), and that these measures are tailored to the individual and their environment (Bower & McLellan 1994).

In the last decade a number of new outcome measurement tools have been developed. Those tools considered best practice include—Goal Attainment Scaling (GAS); Canadian Occupational Performance Measure (COPM); Gross Motor Function Measure (GMFM); and the Pediatric Evaluation of Disability Inventory (PEDI). These tools more sensitively measure the small but meaningful changes made by people with disabilities in response to therapy, including people with cerebral palsy. This makes clinical effectiveness research more feasible and means that change in response to therapy is more likely to be detected when present.

The suite of instruments available to researchers and clinicians is expanding. Some newer tools specifically measure the participation dimension of the ICF framework, such as the Children’s Assessment of Participation and Enjoyment , and what children with cerebral palsy ‘do do’ in real life rather than what they ‘can do’ in a clinic setting, for example the

Assisting Hand Assessment . The sensitivity to change in these newer tools is yet to be established and therefore these additional measures will not be described here.

Goal Attainment Scaling

GAS is an individualised measure of clinical change using quantifiable goals (Kiresuk & Sherman 1968). This measurement tool is used to evaluate functional change following a specified period of therapy in relation to defined individualised goals and a range of potential outcomes (King et al. 1999).

GAS can be used to measure both individual and program outcomes from therapy—firstly, individualised services and secondly, the effectiveness of a service as a whole (King et al. 1999). This tool is recognised as a way of capturing small but significant clinical change which may otherwise be missed when using global, standardised assessment procedures (King et al. 1999; Ottenbacher & Cusick 1990; Palisano et al. 1992; Palisano 1993; Wallen & Doyle 1996). Goal attainment also has the added benefit of adopting a collaborative family-centred approach (King et al. 1999).

Canadian Occupational Performance Measure

COPM is an individualised outcome measure used to detect change in functional performance goals based on the individual's perceptions and priorities (Law et al. 1990). The tool conceptualises 'occupational performance' as self-care, productivity and leisure, which is influenced by the person's social roles, their environment and their personal views both about self 'performance' and 'satisfaction' with performance (Canadian Association of Occupational Therapy 2002).

Changes in functional performance goals are measured using semi-structured interviews whereby the person rates their performance and satisfaction with their performance in specified problem areas, and over a period of time (Law et al. 1994a, 1994b). The tool was originally designed for use with adults (Law et al. 1990) but has also been used to measure the effectiveness of intervention with families and children with cerebral palsy (Law et al. 1997; 1998). The generic nature of the COPM has enabled it being successfully adopted in many specialities for measuring individual change, assessing program impact and for quality assurance (Law et al. 1997; McColl et al. 2000). Furthermore, it has been shown to be sensitive to change in function as perceived by families and therapists (Law et al. 1994a), especially in the domains of self-care, play and mobility (Law et al. 1998).

Gross Motor Function Measure

GMFM is a criterion-referenced outcome measure that evaluates change in movement function in children (Russell et al. 1989; 1993). The tool was specifically designed for children with cerebral palsy (Palisano et al. 2000).

There are five separate sub-domains to the GMFM, which evaluate different types of movement (Russell et al. 1989; 1993). These movements include: lying and rolling; sitting; crawling and kneeling; standing; and walking, running and jumping. A child is scored in their ability to perform these activities.

The GMFM is considered a clinically useful and reliable instrument for assessing movement function and therapy outcomes (Nordmark et al. 1997). It is now considered the gold standard measurement tool for children with cerebral palsy when measuring movement (Ketelaar et al. 1998).

Pediatric Evaluation of Disability Inventory

PEDI is a standardised measurement tool that measures the acquisition of self-care, mobility and social function skills of children with physical disabilities (Henderson & Pehoski 1995). The tool identifies the child's typical functional ability, the amount of assistance they require from their caregivers and the supportive equipment they use to help with the task (Ketelaar et al. 1998).

The PEDI has three functions: (1) to detect functional deficits; (2) to monitor progress in paediatric therapy programs; and (3) to evaluate program outcomes as a whole (Haley et al. 1992). Many authors have described the usefulness of the PEDI in evaluating the functional skills of children with physical disabilities (Nichols & Case-Smith 1996; Ziviani & Wright 1995), including children with cerebral palsy (Ketelaar et al. 1998; Russman et al. 1997). This is because the instrument is sensitive to clinical change in populations where the disability is life-long rather than acute (Ketelaar et al. 1998; Nordmark et al. 2000). A review of measurement tools for children with cerebral palsy found that the PEDI was the only self-care instrument to demonstrate sensitivity to detecting clinical change over a six month period of time (Ketelaar et al. 1998).

Therapeutic techniques and their efficacy

When considering effectiveness of therapy, the following questions are relevant.

- What type of therapy is effective?
- At what intensity is therapy effective?
- What method of delivering therapy is effective (direct or supervised)?
- Are there subgroups in the population who benefit more from therapy?

These questions are not easily answered. It can be difficult to evaluate the effectiveness of therapy for a number of reasons. Chief among them is that treatment is not delivered in a standardised manner—administered under controlled conditions using specific procedures—and is not a readily quantifiable process that can be prescribed in discrete units (Michaud 2004). Other problems associated with evaluating therapy include the following.

- There are different types and severities of cerebral palsy and consequently the functional abilities of people with cerebral palsy vary immensely. While a heterogeneous sample increases the generalisability of the results, it can also make it more difficult to detect significant effects; there may be subgroups in the study sample for whom the treatment was effective, but the effect may be obscured in the group analysis (Bower & McLellan 1994, Butler & Darrah 2001).
- Randomised clinical trials are viewed by some as the ideal method for determining the effectiveness of a treatment method (Butler et al. 1999), but such trials are often difficult to perform for practical and ethical reasons and, as a result, many studies employ less well-controlled research designs. For example, many studies fail to include a control group, which decreases confidence in the results as the findings of these studies may have been due to chance rather than due to the treatment itself. When studies do include a control group, the intervention of interest is most often compared to some other intervention, since assigning participants to a control group that does not receive treatment is considered by most to be unethical. Consequently, the results of these studies are relative to another treatment rather than no treatment at all.

- It is difficult to measure treatment change when there is ongoing change in participants due to the process of growth and maturation (Bower & McLellan 1994; Michaud 2004).
- It is difficult to recruit large subject numbers. Small sample sizes means the power of studies to detect differences that exist is low. Furthermore, using a widely dispersed population of people with cerebral palsy and therapists to combat the small sample size increases the variability of both intervention and assessment (Bower & McLellan 1994). The use of small sample sizes, coupled with inadequate description of the study population can make it difficult to determine if therapy is effective for certain subgroups (Darrah et al. 2004a).
- Evaluating the effectiveness of therapy is often confounded by such things as the combination of different therapy types and medical interventions, and the fact that no two therapists are identical in their approach, skills, experiences or resources (Butler & Darrah 2001).
- The quality and amount of therapy administered outside the study by caregivers is rarely considered (Kanda et al. 2004).
- Therapy is given for different reasons to different clients and so researchers often have different outcomes of interest and use different instruments to measure them (Butler & Darrah 2001). There is also the problem of researchers using outcome measures that do not have any proven validity and reliability (Bower & McLellan 1994).
- Studies often do not measure dimensions of activity and participation or environmental factors, and so do not capture the full nature of the life experiences of the person with cerebral palsy.

Because of these difficulties, there is a paucity of randomised controlled trials and systematic reviews to guide practice (Boyd et al. 2001). Although the number of outcome studies being conducted has increased three-fold over the last 10 years (Majnemer & Mazer 2004), some common therapy techniques for people with cerebral palsy still lack conclusive experimental evidence to support their effectiveness (Siebes et al. 2002). Attempts have been made to aggregate findings across whole therapy disciplines in systematic reviews and meta analyses, which have resulted in authors concluding that there is insufficient evidence to support or reject the hypothesis that therapy is effective (Pennington et al. 2005; Steultjens et al. 2004). There is also little evidence that demonstrates the superiority of one therapeutic technique over another, making evidence-based decision-making difficult for clinicians and family members (Mayston 2005). In the absence of strong conclusive evidence, people with cerebral palsy, parents and caregivers must consider other important aspects of therapy, such as cost, accessibility, time and the effect of the intervention on the family and individual when deciding the type of therapy to use (Darrah et al. 2004a).The limitations in the existing evidence base do not mean that therapy is not effective; instead, they indicate areas in which further research is needed (Butler & Darrah 2001; Darrah et al. 2004a). Furthermore, caution should be exercised when interpreting non-significant statistical results, as a lack of significance may be due to inadequate power in the study design rather than absence of a real effect (Darrah et al. 2004a).

Studies have shown that interventions aimed at the impairment level can improve activity performance (Andersson et al. 2003; Dodd et al. 2002; 2003). For example, strength training targeting specific muscles can improve walking ability. Thus, some extrapolation 'up' of the effects of impairment-based interventions is often made (for example, hippotherapy—horse riding— may improve movement-related functions, interpersonal interactions and relationships, and participation in community social life). Table 3.2 summarises the various techniques used by therapists to assist people with cerebral palsy in reaching their therapeutic goals, and the level of research evidence supporting each technique; the table is structured using the ICF components of body functions and structures, activities and participation, and the environment. Three categories of level of research evidence are used in the table: systematic review, randomised controlled trial and lower levels of evidence; efficacy is best established through randomised controlled trial designs (Herbert et al. 2005). In addition, a notation is assigned alongside the level of evidence: '+' meaning positive supportive evidence; '-' meaning the evidence suggests the approach is ineffective, and '?' meaning the researchers concluded there was not enough positive or negative evidence to develop a firm viewpoint about the effectiveness of the technique.

Table 3.2: Effectiveness of specified therapeutic interventions

Therapeutic intervention	Evidence
Body functions and structures	
Strength training Aim: establish/restore muscle strength Description: A series of exercises which provide progressive resistance to muscles designed to improve independent movement and endurance.	Systematic review + Dodd et al. 2003; Morton et al. 2005
Casting Aim: establish/restore muscle length and *prevent* joint contracture Description: Casts are made from fibreglass or plaster of paris and are used to hold a body part in a certain position to stretch the immobilised muscle.	Systematic review + Teplicky et al. 2002
Neuro-developmental therapy (NDT) Aim: establish/restore normal motor development Description: Specific handling techniques are used to inhibit 'abnormal' movement patterns and facilitate 'normal' movement. Movement patterns which are addressed often relate to functional, everyday activities.	Systematic review – Brown & Burns 2001 NB: Assumes change in impairments would lead to functional improvements (Law et el. 1998). Empirical evidence is failing to show that NDT generalises to every day contexts.
Stretching/range of motion exercises Aim: prevent joint contracture Description: Stretching can be performed passively (by an external person or with equipment) or actively (by the client) by holding a muscle in a stretched position.	Systematic review ? Harvey et al. 2002 RCT – Lannin et al. 2003 NB: Effective in normal population, unclear in cerebral palsy population
Biofeedback Aim: establish/restore movement through feedback Description: Provides feedback (visually or auditory) on muscle activity via a machine.	Lower level + Dursun et al. 2004
Electrical stimulation Aim: establish/restore muscle strength Description: Causes passive muscle contraction via electrical pulses through electrodes, which can be surface or implanted.	RCT – Chan & Smith 2004; Sommerfelt et al. 2001; van der Linden et al. 2003
Massage Aim: establish/restore range of movement by muscle relaxation Description: Manipulation of soft tissue for relaxation, to reduce spasticity, restore and maintain soft tissues and relieve pain.	Lower level + Hernandez-Reif et al. 2005; McLellan et al. 2005; Stewart 2000
Oral sensorimotor therapy Aim: establish/restore oral coordination for eating Description: Exercise and stimulation to address coordination of oral movements and saliva control for people with dysphagia.	Lower level + Hemsley & Balandin 2003; Rogers 2004
Phonological awareness and articulation therapy Aim: establish/restore formation of sounds Description: Exercises and stimulation to address expressive language foundational skills.	RCT + Law et al. 2003; Sunderland 2004

(continued)

Table 3.2 (continued): Effectiveness of specified therapeutic interventions

Therapeutic intervention	Evidence
Vojta Aim: establish/ restore regulation of body posture Description: Via 'reflexlocomotion' facilitates the automatic regulation of posture and coordination of limb movement.	RCT ? D'Avignon et al. 1981 Lower level: + Barry 1996
Activities	
Hydrotherapy/aquatic therapy Aim: establish/restore muscle relaxation and muscle strength Description: Aquatic therapy is water-based therapy in a heated pool. Via the warm water the therapy decreases muscle spasm, relaxes muscles, relieves pain and can increase range of motion. Water changes the effect of gravity making it easier to practice movement.	Lower level + Kelly & Darrah 2005
Constraint induced movement therapy Aim: establish/restore functional non-dominant arm movement Description: Increase use of the non-dominant arm by constraining the dominant arm using a mitt, sling or cast while providing simultaneous intensive practice of movements in the non-dominant arm.	RCT + Gordon et al. 2005; Siegert et al. 2004; Taub et al. 2004
Dysphagia management Aim: adapt/modify swallowing difficulties and resultant nutritional deficiencies Description: Management for feeding and swallowing disorders may involve advice on specific food preparation, including altering the consistency of foods and diverse menu planning to ensure that sufficient calories and nutrients are being ingested either orally or via tube feeding.	Systematic review ? Hemsley & Balandin 2003; Sleigh et al. 2004
Communication training Aim: establish/restore comprehension, expression and use of language Description: Various interventions are employed, including: operant and micro-teaching methods addressing communication skills such as maintaining eye contact and head control and requesting objects; expressive language interventions (for example, language stimulation and word mapping); and interventions targeting receptive language difficulties.	Systematic review ? Dixon et al. 2001; Girolametto et al. 1999; Law et al. 2003; Pennington et al. 2005
Handwriting training Aim: establish/restore handwriting skills or determine alternative output Description: Practice at handwriting using movement teaching techniques and prescription of adaptive equipment, for example, pencil grips.	RCT + Sudsawad et al. 2002
Conductive education Aim: establish/restore independence in the classroom Description: Based in the educational model, the 'conductor' uses highly structured group activities divided into task specific/functional steps; rhyme and song to stimulate movement, with minimal aids and equipment.	Systematic review ? Darrah et al. 2004a RCT +/– Bochner et al. 1999; Reddihough et al. 1998 NB: Outcomes same as NDT but less than therapy
Functional training Aim: establish/restore functional skills of daily living Description: Practice of functional activities such as walking, dressing in everyday environments.	RCT (small) + Ketelaar et al. 2001

(continued)

Table 3.2 (continued): Effectiveness of specified therapeutic interventions

Therapeutic intervention	Evidence
Play therapy Aim: establish/restore play and recreation and an integral part of development Description: Play is used as a means to engage a child in tasks and actions that are designed to improve physical functioning. Actions may be repeated to achieve the outcomes set by the game, or a game may be used as a distraction from the intended functional activity. For example, a child may have to maintain a certain posture in order to fulfill the aim of a game, or favourite toys may be incorporated into a session to increase motivation.	RCT (low power) + Hanzlik 1989 Lower level + Holder 2001; Rogers & Zivianni 1999
Home programs Aim: adapt/modify task demands and parenting expertise to achieve functional outcomes at home Description: Strategies and supports given to the family to enhance the child's development and parenting expertise.	Lower level + Novak et al. (in press) RCT underway Novak et al. (in press)
Positive behavioural support Aim: establish/restore child's behaviour, adapt/modify parenting behaviour and prevent parent stress Description: Children with CP are 5.3 times more likely to have behavioural problems, such as, anxiety, hyperactivity, dependence and group conflict than their peers. Positive behaviour support provides training and support to parents about effective parenting. Key aspects of the technique include: safe and engaging environments; positive learning environments; assertive discipline; realistic expectations; and taking care of parents.	RCT + Crisante 2003; Saunders et al 2003a, 2003b; Turner & Saunders 2006
Participation	
Hippotherapy AIM: establish/restore normal pelvis movement for walking DESCRIPTION: Horse riding is used to improve balance, postural control, coordination, range of motion and all movement (including walking). The rhythmical movements of the horse stimulate the rider's pelvis movement to improve walking.	RCT (small) +/– Benda et al. 2003 ; MacKinnon et al. 1995 ; McPhail et al. 1998 ; Sterba et al. 2002
Physical activity and sports therapy Aim: create positive community attitudes towards participation Description: Exercise is considered as a form of intervention for children and adolescents and adults with cerebral palsy, and can improve levels of energy, muscle strength, aerobic fitness and gross motor function.	RCT + Allen et al. 2004; Damiano & Abel 1998; Darrah et al. 2004b; Kelly & Darrah 2005; van den Berg-Emons et al. 1998
Swimming Aim: establish/restore moving without support in the water, increasing muscle strength; range of joint movement; coordination; balance and fitness Description: Provides continuity from rehabilitation to recreation or competition. In the pool a person with a disability can enjoy the activity on the same terms as other members of their family and friends, so there are both social and physical benefits.	Lower level + Kelly & Darrah 2005
Environment	
Postural control/ positioning Aim: adapt/ modify the person's seat to enable the upright posture Description: Prescription and manufacture of customised seating cushions with a wheelchair or stroller and/or provision of postural adjustments to enable upright sitting for function and arm use.	Systematic review + Farley et al. 2003

(continued)

Table 3.2 (continued): Effectiveness of specified therapeutic interventions

Therapeutic intervention	Evidence
Orthotics Aim: adapt/modify a joint and muscle position for alignment or stretch or to prevent contracture Description: Foot and or hand orthoses are external supports/assistive devices fixed externally to the human body for the treatment of neuromuscular and musculoskeletal impairments. An ankle foot orthosis (AFO) is commonly used in the management of cerebral palsy to improve functional activities such as the clearance of the foot in walking.	Systematic review +/? Teplicky et al. 2002 RCT – Satkunam 2003
Alternative augmentative communication (AAC) Aim: adapt/modify communication to enhance or replace natural speech Description: AAC can involve a diverse range of methods; natural communication (such as pointing), signing, symbols and object cards and voice output communication devices. These methods can assist people who may be unable to produce speech well enough to communicate naturally and can increase socialisation, participation and learning.	Systematic review ? Novita 2006; Pennington et al. 2005 NB: Need for higher quality studies
Products and technology Aim: adapt/modify task demands to improve independence Description: Mobility aids can include wheelchairs, powered wheelchairs, walkers, scooters and vehicle modifications. Environmental control systems include an alternative switching device which can activate and control aspects of the environment. These systems are often used in the home and enable people with disabilities to have greater independence over operating household appliances and/or settings (such as lights). Switches can be activated by actions such as blinking or speaking. The greater the severity of CP the greater the number of products used. Products increase independence in mobility, self-care and social function, they also reduce caregiving burden.	Lower level + Berry & Ignash 2003; Craig et al. 2002; Østensjø et al. 2005
Training, information sharing and support Aim: adapt/modify task demands by empowering person's significant others with new information and skills Description: The training of persons working or living with a child of school age is an important component of a therapist's role. This can involve the training of teachers, aides, carers and parents on numerous topics including, the specific condition/s and needs of a child. This training can include supporting inclusion and promoting positive attitudes. Therapists may adapt the learning environment (for example, appropriate seating, accessibility) and integrate therapeutic strategies into curriculum. Components of parental education include: assisting with development, communication partner training and, the encouragement of parent's skills to engage their children in play and everyday social interaction.	Systematic review + Barlow & Parsons 2003; Bennett et al. 1997; Mahon & Cusack 2002; Mahoney et al. 1999; Pennington et al. 2004
Parent counselling Aim: assist parents in dealing with issues associated with having a child with a disability Description: Therapy may involve counselling for any range of issues including coping with stress and other psychological demands, formal and informal relationships and personal and social issues. These sessions may be held on an individual or group basis and can involve general education, cognitive behavioural counselling, problem solving and work dealing with emotions	Systematic review + Barlow et al. 2003; Rousso 1982; Schaller & Garza 1999

Note: Level of evidence is characterised as systematic review, randomised clinical trial (RCT) or lower level of evidence (lower level). A '+' denotes positive support evidence; '-' denotes the evidence does not support effectiveness and '?' denotes neither a positive or negative result.

At what intensity is therapy effective?

It has been suggested that the intensity of therapy, that is the number of therapy sessions within a set period of time (Bower et al. 2001), may be a key variable in studies examining the effectiveness of therapy. Parents, therapists, teachers and people with cerebral palsy often state that motor skill acquisition would increase more rapidly if more therapy was provided to people with cerebral palsy (Bower et al. 1996).

To date, however, there is inconclusive evidence that intensive amounts of any particular therapeutic approach are more advantageous than 'routine' amounts of therapy (Stanger & Oresic 2003). The results from a randomised controlled trial investigating the effectiveness of physiotherapy found that intensive amounts of therapy (that is, one hour of physiotherapy five times per week) over a six month period was considered tiring and stressful by many participants and their families, and often resulted in low compliance (Bower et al. 2001). A more recent study has found that an intermittent intensive program of four sessions of physiotherapy and occupational therapy per week for four weeks followed by an eight week rest period was well tolerated among participants and led to improvements in motor function that were maintained over the rest periods (Trahan & Malouin 2002). Further research using a more rigorous study design is needed to confirm these preliminary findings.

The duration of treatment is another important factor for assessing effectiveness of therapy interventions. However, no literature exists as to how long therapy needs to be given to achieve optimal outcomes (Kanda et al. 2004). The duration, intensity and frequency of therapy may also play a role in determining a client's progress towards certain goals and the effectiveness of interventions (Bower & McLellan 1992; Bower et al. 1996; 2001; Trahan & Malouin 2002). While there is some suggestion that more intensive, intermittent therapy (interspersed with long rest periods) may be effective in certain circumstances, the lack of research on the long term outcomes and sustainability of this approach, and the unique profile of people with cerebral palsy, make it difficult to generalise findings.

Recommendations for measuring effectiveness

The lack of conclusive evidence regarding the effectiveness of some therapy techniques (Table 3.2) for people with cerebral palsy has lead researchers to recommend the way forward to overcome many of the methodological limitations so prevalent among studies. In a review of the effectiveness of neuro-developmental therapy for children with cerebral palsy, Butler and Darrah (2001) propose future studies 'need to include clearly defined, homogenous participants, operationally defined treatment techniques and appropriate outcome measures in samples with adequate power'.

Darrah and colleagues (2004a) suggest that research needs to be focused on identifying optimal intervention strategies for a very clearly defined clinical profile. Some 10 years earlier, in a review of the literature investigating effectiveness of cerebral palsy, Bower and McLellan (1994) suggested using 'a representative series of case studies with individual goal setting and a validated outcome measurement, using randomised treatment' to overcome many of the methodological limitations of published studies. A series of controlled single case studies is believed to be more beneficial than large group study designs for conditions in which the problem and its solution varies from case to case (Bower & McLellan 1994). This approach also has the advantage of requiring a smaller number of subjects, although an appropriate number and range of individual cases should be included.

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.

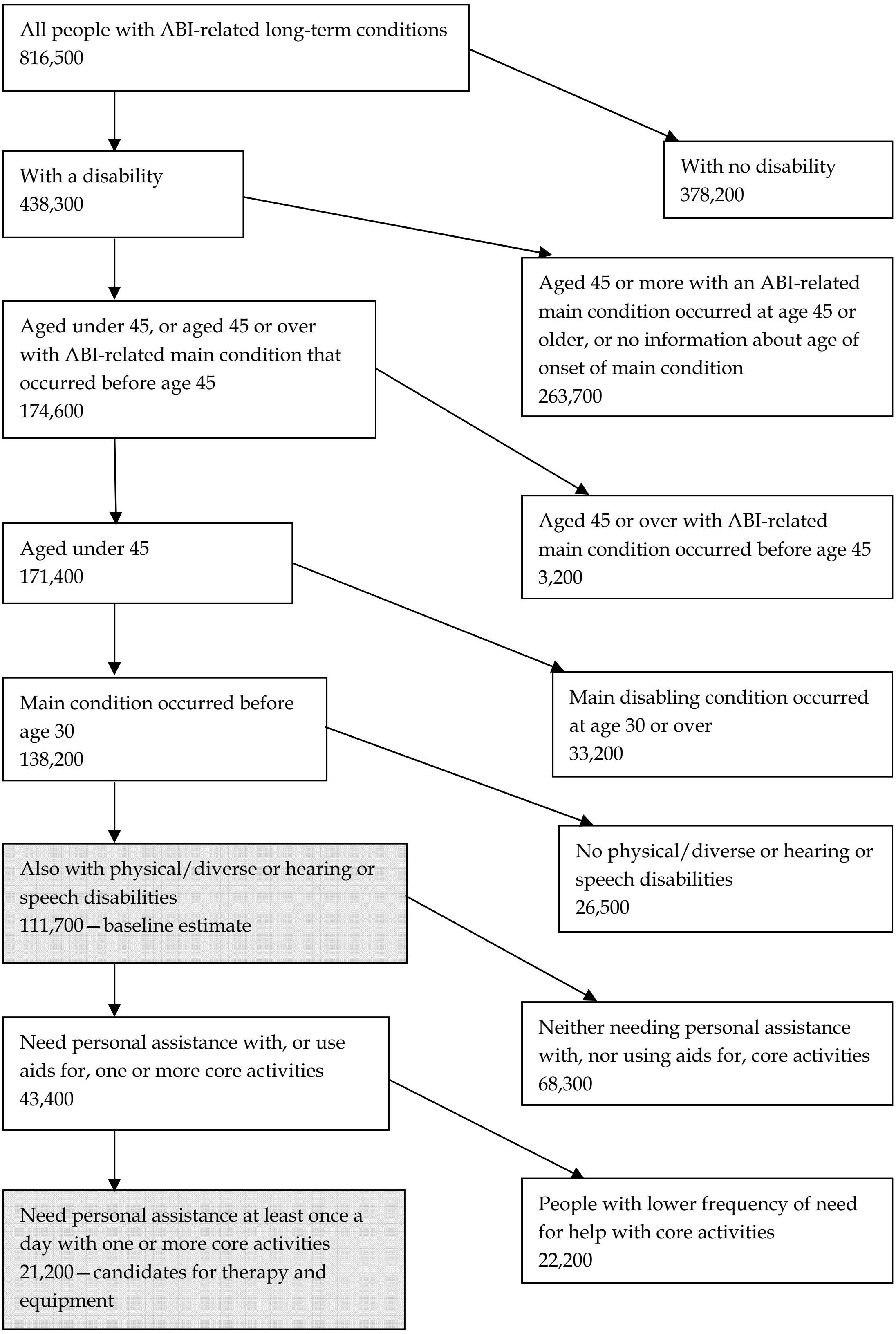

Figure 4.1: Step-by-step exclusion process for baseline estimates of cerebral palsy-like disabilities and candidates for therapy and equipment, 2003

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.

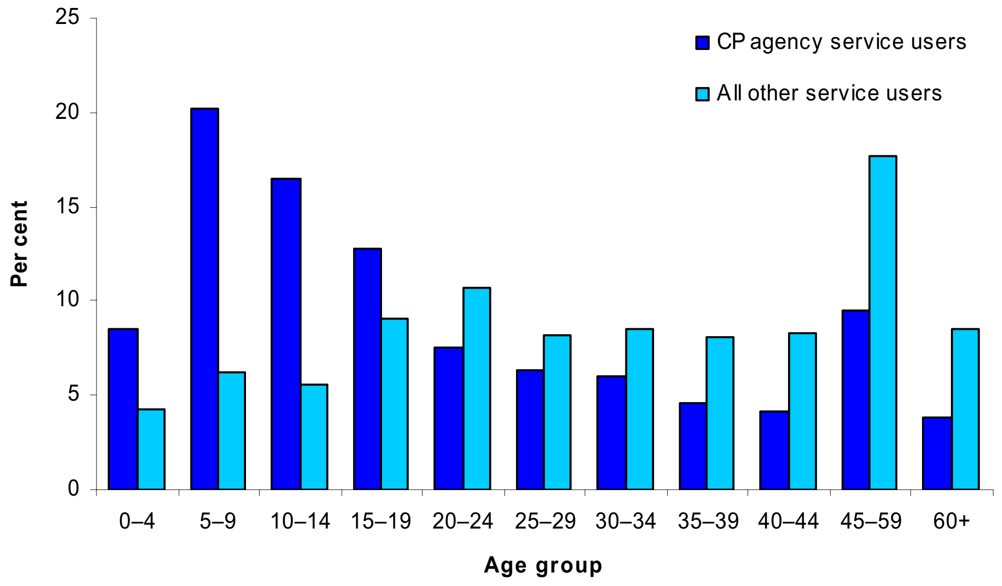
Source: AIHW 2005:6.

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

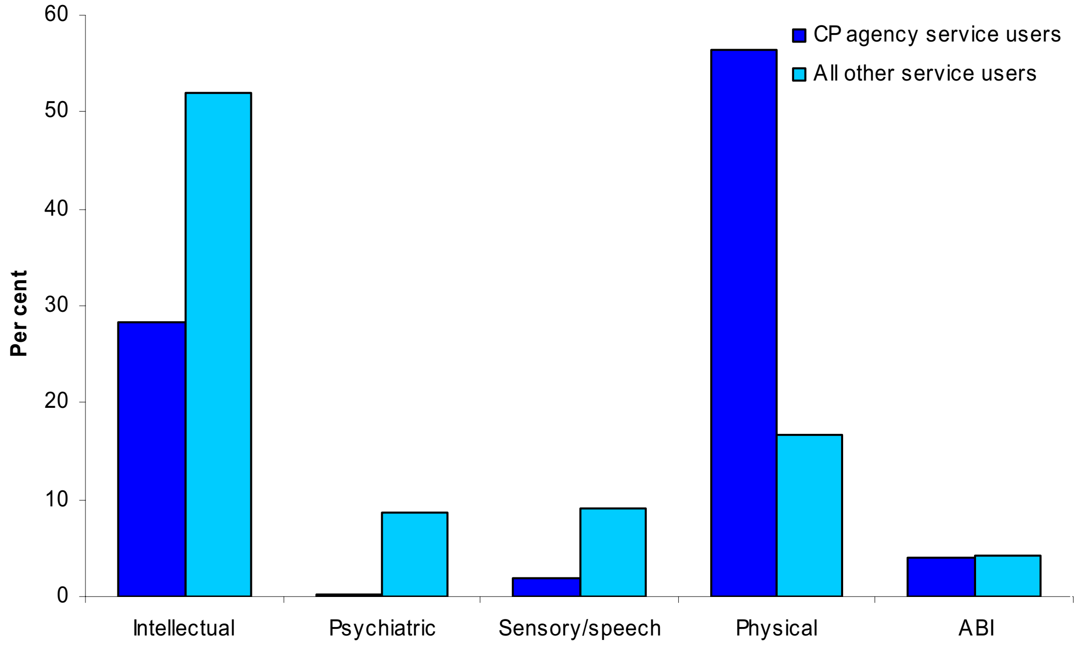
Figure 6.1: Age distribution: comparison of CP agency service users and all other service users, 1 July 2003–30 June 2004 (per cent)

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.

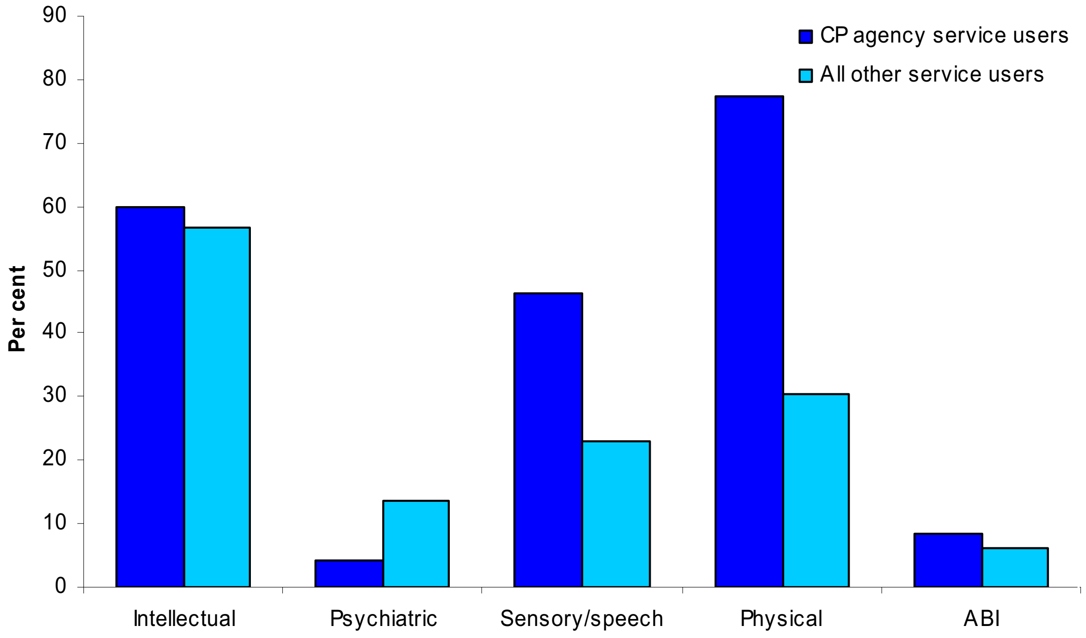
When all significant disability groups are considered, a greater proportion of CP agency service users had physical disability than all other users (77% compared to 30%); over half of both user groups had intellectual disability (60% and 57%, respectively) and 46% of CP agency service users and 23% of 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)

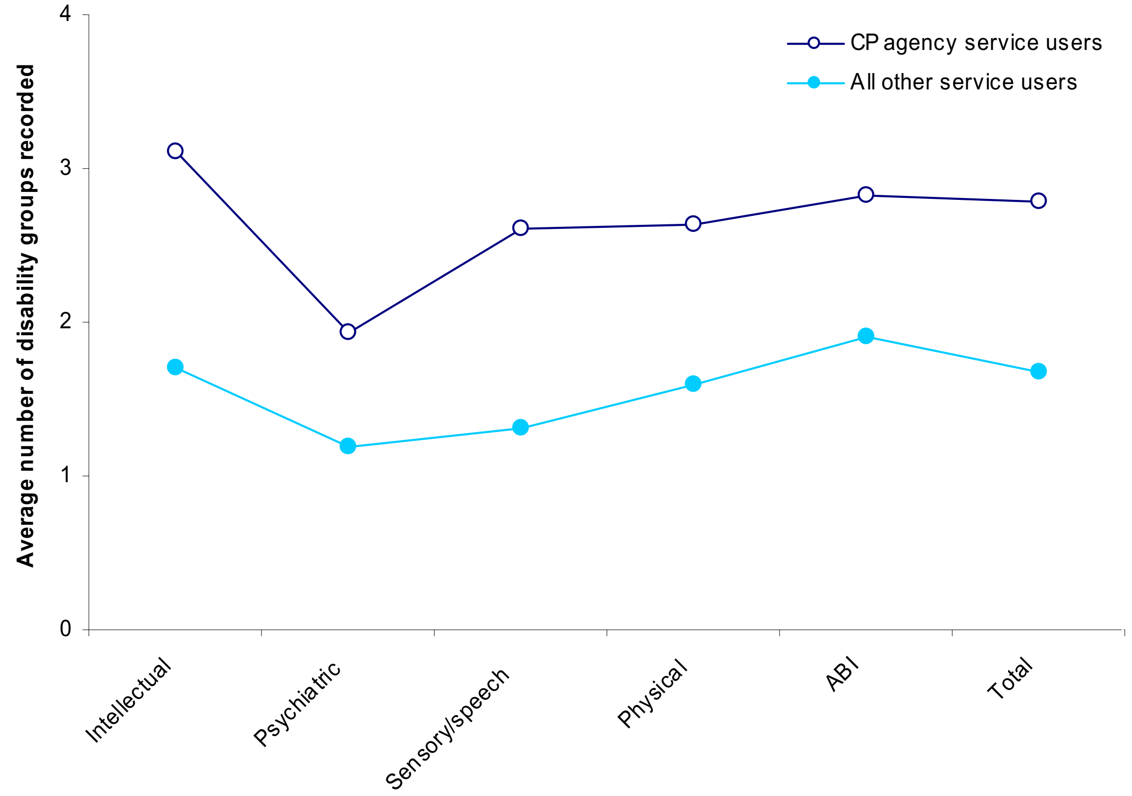


Figure 6.4: Average number of disability groups recorded by primary disability group: comparison of CP agency service users and all other service users, 1 July 2003–30 June 2004

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*

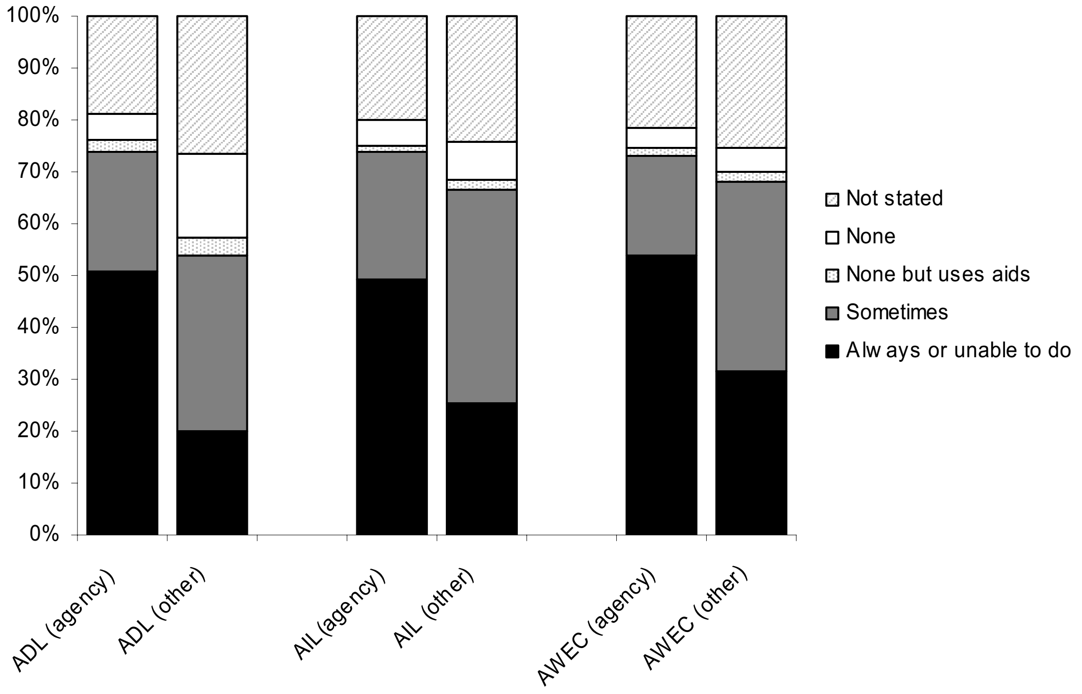


Figure 6.5: Comparison of service users' support needs, CP agency service users and all other service users, 1 July 2003 – 30 June 2004

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).

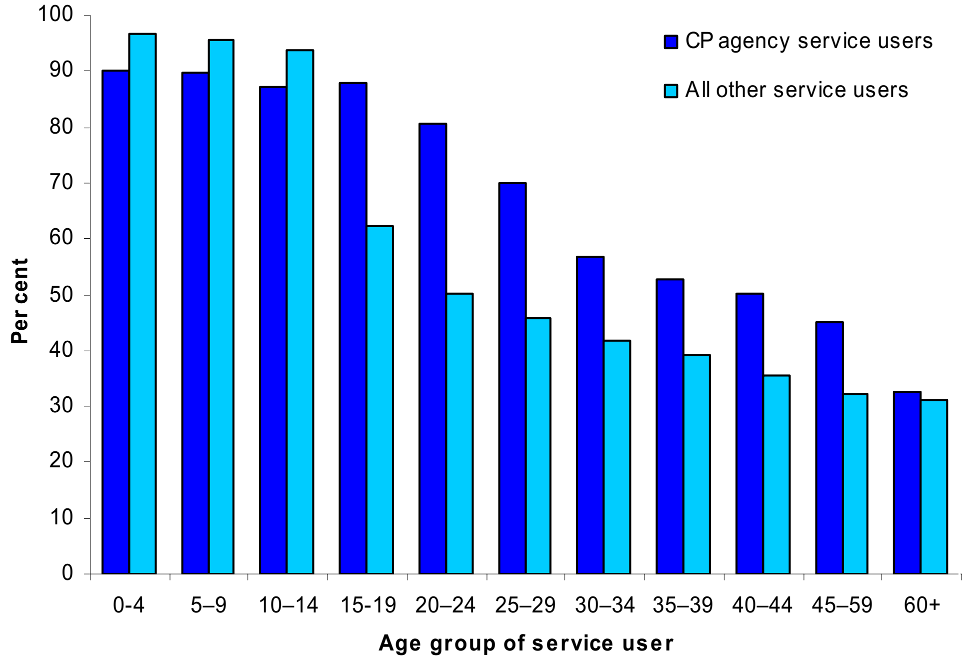
A higher proportion of CP agency service users above 14 years reported an informal carer (Figure 6.6). For service users under 14, there was relatively little difference between CP agency service users and all other service users, while the difference was most marked for users aged 15–29.

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.

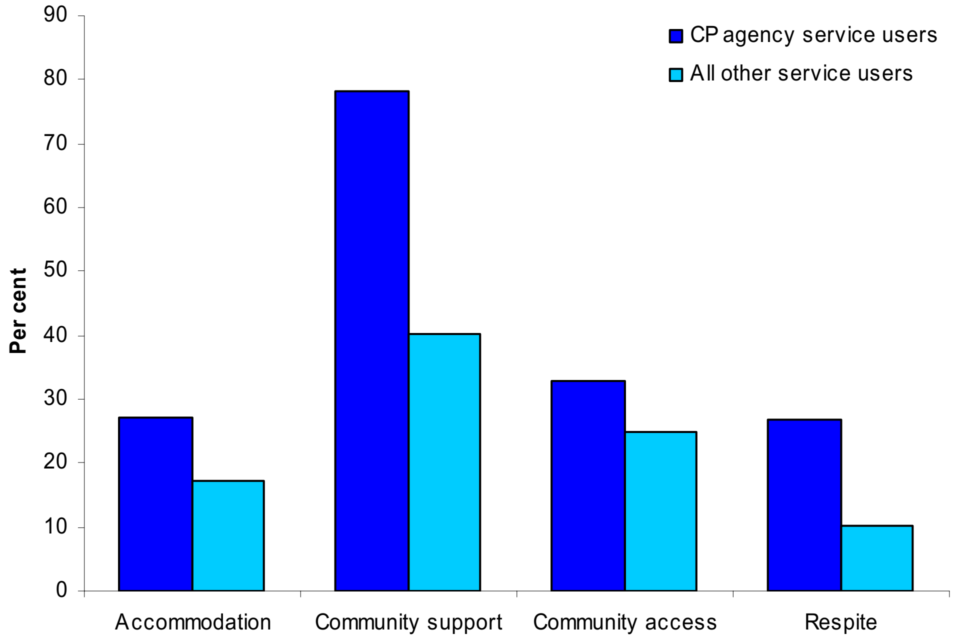
Source: Table A6.6

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.

7 National population data on needs for assistance

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

This pattern is broadly consistent with the CSTDA support needs data presented in Chapter 6—over half of all CP agency service users needed help in all three core activity areas, compared with 26% of all other service users. This provides important support for an assumption employed in two of the methods of estimating the cost of unmet need for therapy among people with CP and like disabilities presented in Chapter 9, namely that need for help with core activities is an indicator of the need for therapy, and that unmet needs for such help indicate unmet needs for therapy (see further discussion in Section 9.3).

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Notes

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Notes

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

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

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

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

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

Notes

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

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

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

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

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

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

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

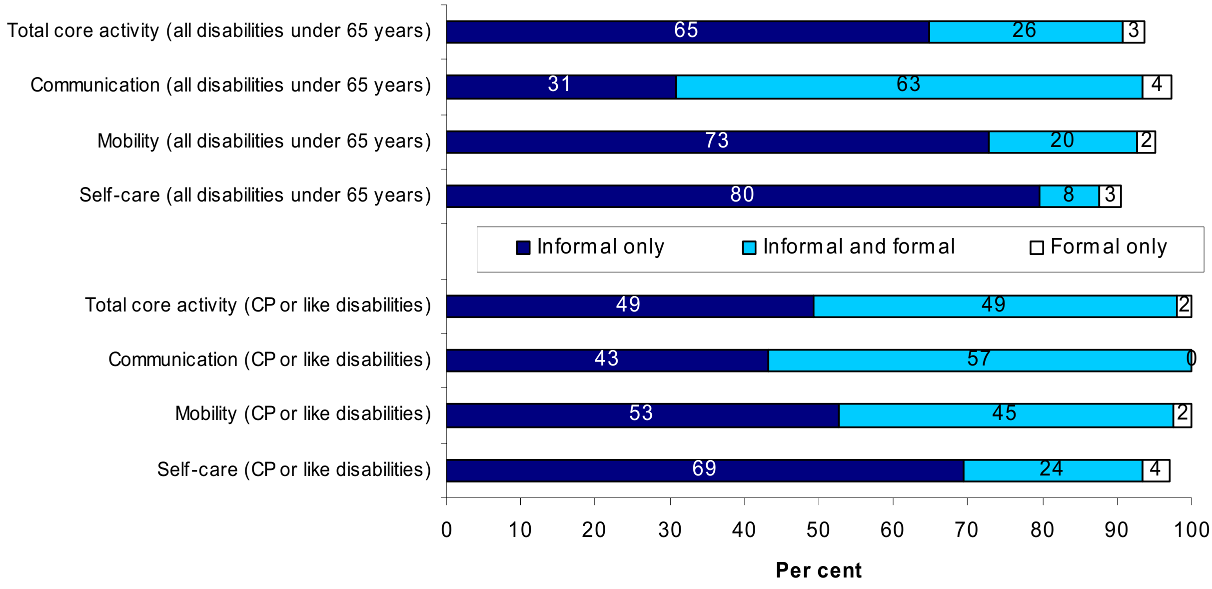
(a) Includes people who need help with at least one core activity.

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

Notes

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

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



Source: Table 7.7; AIHW 2005: Table 5.21.

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

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

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

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

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

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

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

Notes

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

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

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

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

Notes

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

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

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

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

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

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

Notes

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

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

7.3 Conclusion

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

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

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

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

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

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

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

8 Archetypal cases

8.1 Introduction

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

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

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

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

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

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

8.2 Method

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

Definitions of key terms are given in Box 8.1.

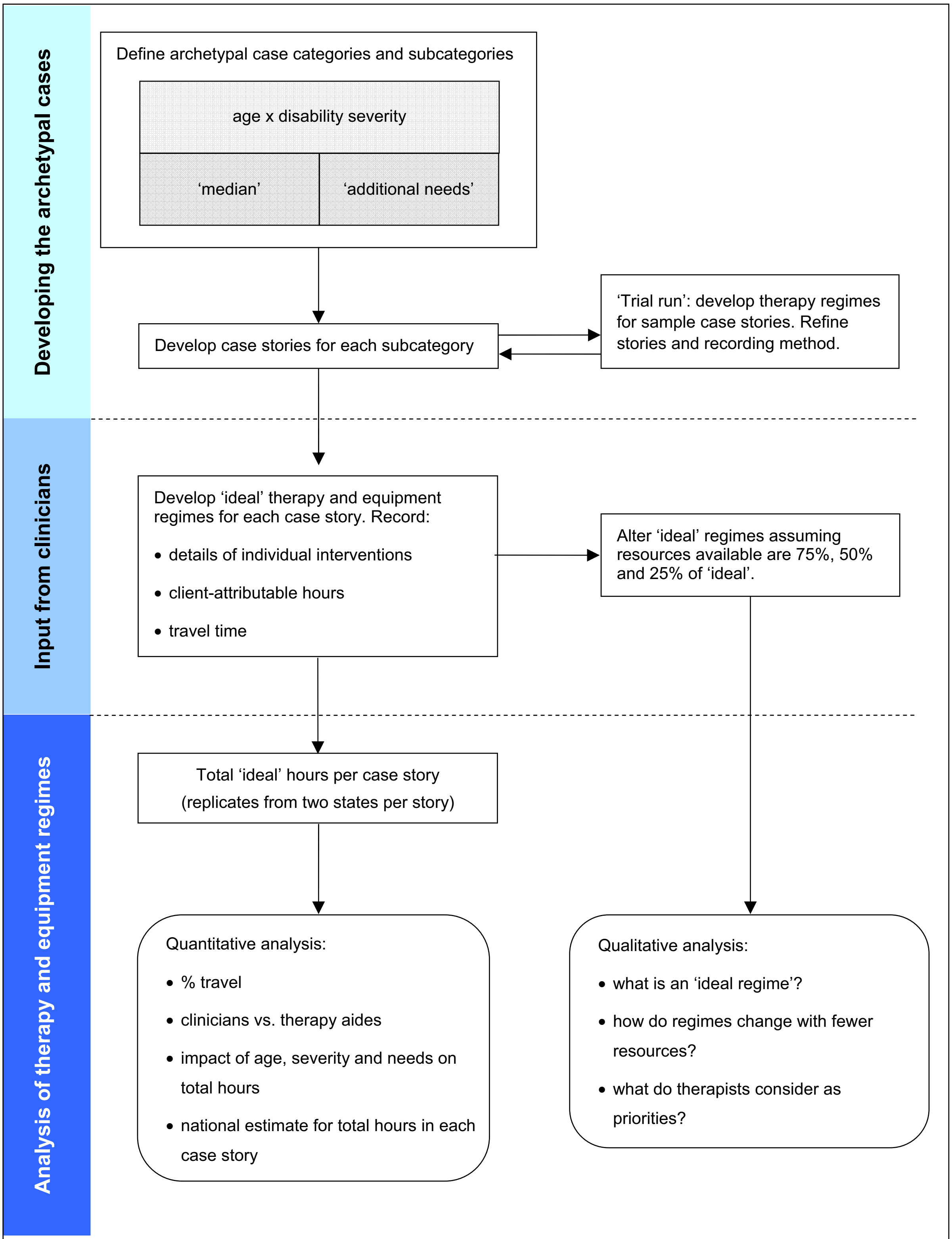


Figure 8.1: Archetypal cases method: developing the archetypal cases and analysing the therapy and equipment regimes

Box 8.1: Key terms relating to archetypal cases

Archetypal case categories*: the nine age-by-severity categories used to divide up the population of people with CP and like disabilities; there are two case stories within each category – a typical 'average' client, and a typical 'additional needs' client.*

Additional needs*: elevated need for therapy for a limited period of time, due to transition points associated with different life stages (such as initial diagnosis, moving into primary or high school, moving out of home), recovery from surgery or acute personal factors.*

Clients: *people with CP or like disabilities who are in contact with CP agencies or other similar specialist services, whether or not currently receiving therapy services.*

Archetypal case categories

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

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

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

The archetypal case categories are:

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

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

Case stories

Within each archetypal case category two case stories were developed:

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

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

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

Developing the therapy and equipment regimes

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

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

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

- Detailed how this ideal regime would be modified if only 75%, 50% and 25% of the therapy resources were available.
- Estimated the proportion of clients (with the age, disability severity, and additional needs status represented by that case story) who were receiving a therapy and equipment regime equivalent to:
  - the 75% regime or more
  - between the 25% regime and 75% regime
  - the 25% regime or less.

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

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

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

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

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

Analysing the therapy and equipment regimes

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

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

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

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

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

8.3 Qualitative analysis of archetypal cases

What does an ideal regime look like?

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

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

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

Box 8.2: Intervention groups

Indirect equipment interventions

- *Researching items*
- *Funding applications*
- *Providing information about options*

Direct equipment interventions

- *Initial assessment of equipment needs*
- *Trialing items*
- *Training in the use of items*

Indirect physiotherapy, occupational therapy and speech pathology

- *Program development*
- *Report writing*
- *Team meetings that do not involve the client*

Direct physiotherapy, occupational therapy and speech pathology

- *Hands-on therapy*
- *Hydrotherapy*
- *Includes school visits where therapy interventions take place*
- *Transport training*

Assessment/review

- *Discipline-specific assessments or reviews, except social work/psychology*
- *Equipment reviews (existing items only)*
- *Environmental assessment*

Social work/psychology

- *Direct social work and psychology sessions with the client*
- *Social work/psychology assessment*
- *Researching and providing information to support the client's participation (for example, links to community services, exploring daytime activities)*

(continued)

Box 8.2 (continued): Intervention groups

Family support

- *Family playgroups*
- *Parental education workshops*
- *Sibling activities*
- *Respite*
- *Social work for family members other than the client*
- *Provision of information to families*

Education and training

- *Training aides or carers*
- *Educating and training school staff*
- *Preparing/distributing school information packages*

Interagency liaison

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

Client/family meetings

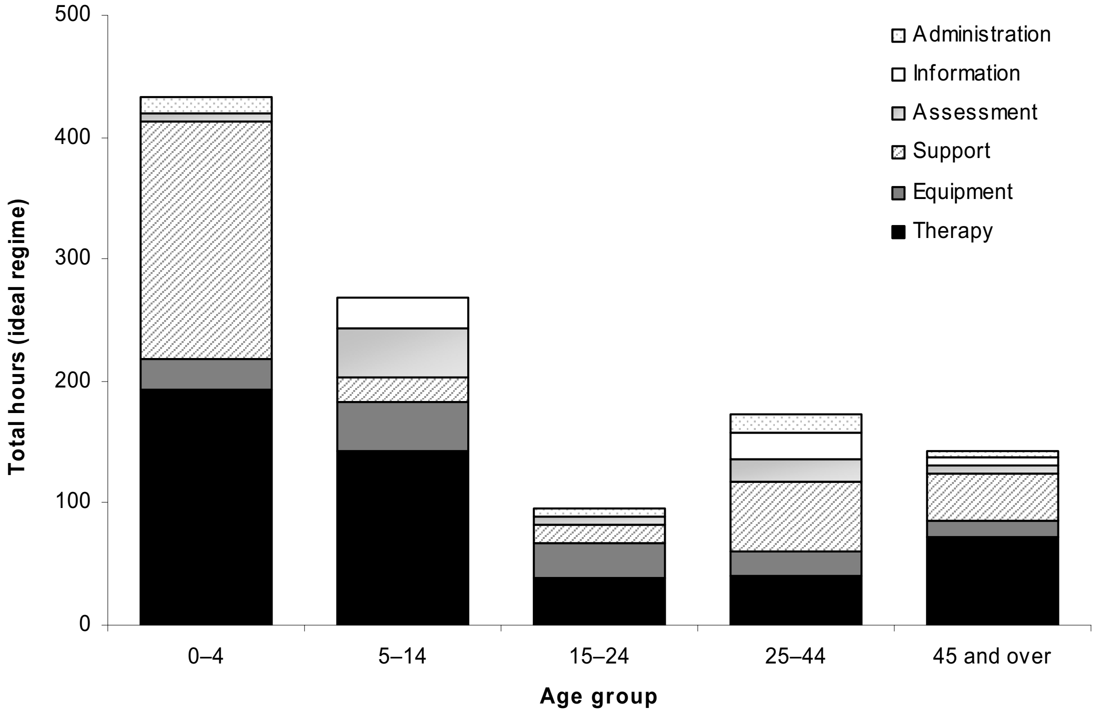
- *All meetings with the client/family*

Administration

- *General documentation*
- *Statistics*

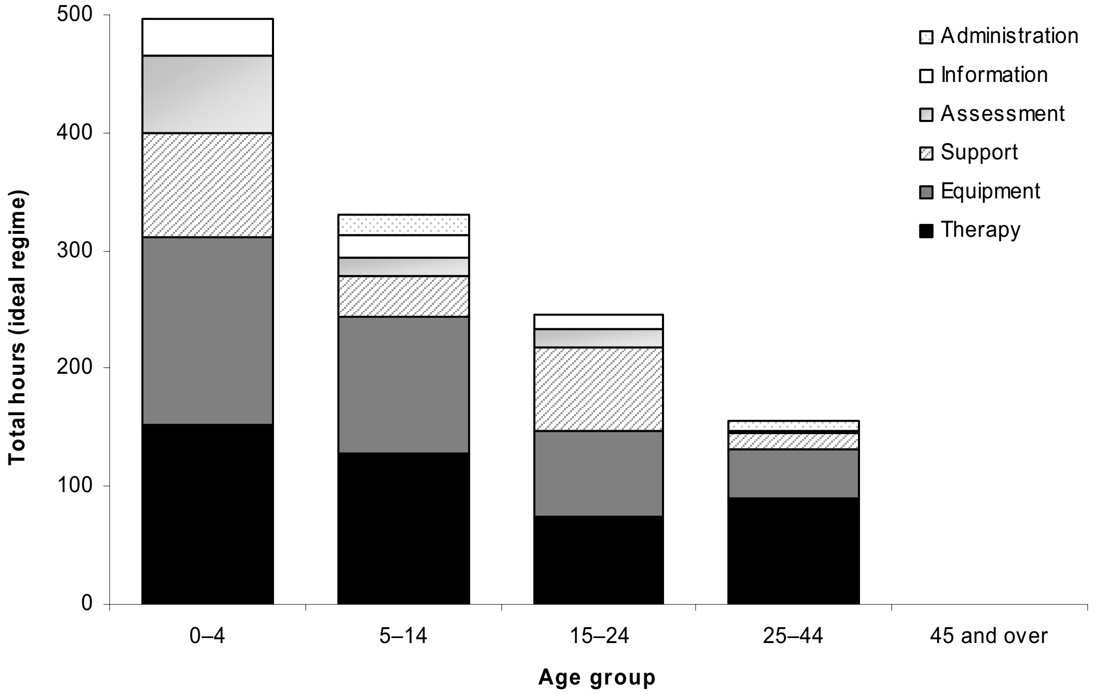
For some analyses it was desirable to reduce the number of groups. Therefore, the groups described above were combined into:

- *'Therapy' (direct and indirect together)*
- *'Equipment' (direct and indirect together)*
- *'Assessment' (assessment/review)*
- *'Support' (family support, social work/psychology, and client/family meetings)*
- *'Information' (education and training, and interagency liaison)*
- *'Administration'*



Note: See Box 8.2 for explanation of the intervention categories used in this figure

Figure 8.2: Mild/moderate disability: breakdown of total hours (ideal regime) by intervention categories, averaged across median and additional needs regimes and state replicates



Note: See Box 8.2 for explanation of the intervention categories used in this figure

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

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

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

Reduced resource regimes

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

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

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

Table 8.2: Deletion of intervention groups in 25% regimes

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

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

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

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

Notes

1. The figures presented in the table are the percentage of total hours made up by different intervention groups, averaged over all regimes that included the group. As not all regimes include all eleven intervention groups, the columns do not sum to 100%.
2. Intervention groups that contribute a greater percentage to total hours in 25% regimes compared to ideal regimes are marked with an arrow pointing up. Intervention groups that contributed a smaller percentage to total hours in 25% regimes than ideal regimes are marked with an arrow pointing down.

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

- Centre-based appointments replaced home visits.
- Meetings between professionals (such as between therapists and hospital staff) were replaced by phone discussions.

- The number of therapists involved in complex interventions decreased.
- Family meetings often involved a single therapist acting in a transdisciplinary role (or else only the discipline relating to the client's area of highest need was represented).
- Interventions were limited to a single goal (for example, speech therapy for mealtime management only, not also for communication).
- Team meetings became discussions between only two therapists.
- Team meetings became as short as 15 minutes.
- In some cases, when the frequency of sessions of a particular type of intervention was reduced, the length of the sessions were increased to partially compensate.
- Giving out information replaced interactive workshops.
- Occasionally aides were used to replace therapists, but as aide training is often required, this was not widely used as a means of reducing resource input.

8.4 Quantitative analysis of archetypal cases

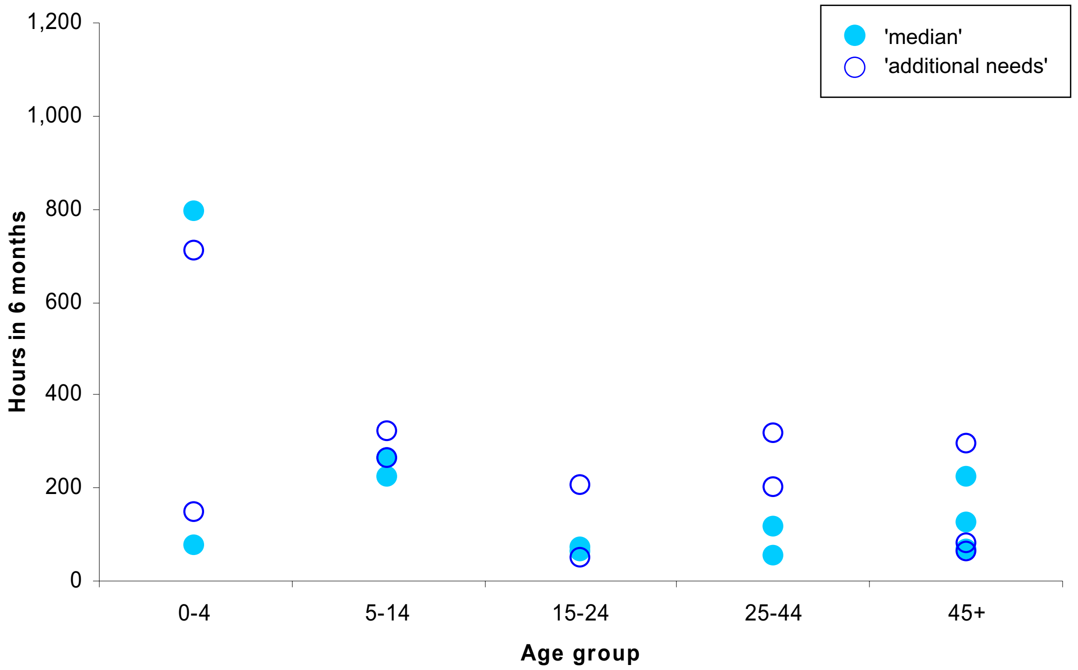
Relationship between age, severity and additional needs on total hours

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

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

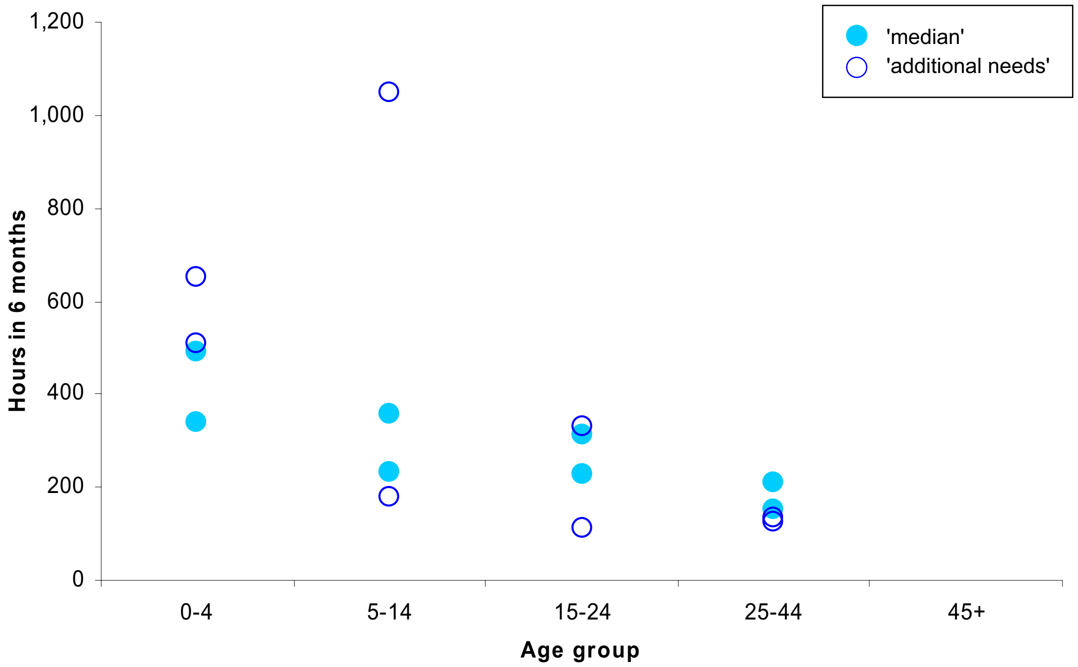
These patterns may reflect therapists' perceptions of greater need for therapy input in younger age groups, which is consistent with the principle of early intervention, that is, that access to therapy and equipment early in life can have an important role in preventing problems later in life. However,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

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



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

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



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

Figure 8.5: Total client attributable hours over 6 months per ideal regime, severe disability case stories

'Additional needs' status did not emerge as a predictor of total hours from the modeling exercise. That is, there was no significant difference between total hours for 'average' and 'additional needs' case stories. Possible reasons for this include:

- A person's additional needs may take priority over and displace ordinary ongoing needs for a period of time, so that different interventions are provided but total therapy time is not greater.
- People with additional needs may be more likely to receive some therapy; that is, they may receive priority over others, rather than receiving more hours. However, this is not reflected in the therapists' estimates of unmet need for 'average' and 'additional needs' clients—see Section 8.6, below.
- Additional needs may be managed by prioritising needs and having targeted episodes of intervention, rather than by adding extra hours—perhaps due in part to staffing realities.
- There may be a temporal 'smoothing' effect in service provision—that is, peaks and troughs are smoothed to avoid overloading clients during a period of additional needs.
- Therapy provided is influenced not only by the person's apparent needs, but also by the family's readiness for therapy.

Differences between states

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

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

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

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

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

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

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

Use of therapy aides

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

Travel time

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

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

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

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

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

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

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

Calculating average total hours for a 6-month period

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

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

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

- Based on advice from expert panel members and CP Australia client data available from two states, it was estimated that approximately 20% of clients in this category would require similar high-technology equipment, and that episodes of high-intensity therapy input to set up the equipment and provide relevant training could be expected to be needed every 5 years (that is, twice within this age range—at entry to primary school and at transition to high school). Thus, in any year, approximately 4% of clients in this category would need an episode of high-intensity intervention.
- On this basis, rather than averaging the two ‘average’ and two ‘additional needs’ replicates in this category, a weighted average was used. The total hours figure for the ‘high’ additional needs replicate was multiplied by 4%, and the average total hours for the two replicates of the ‘average’ case story was multiplied by 96%. The ‘low’ additional needs replicate was excluded from the calculation of an overall average for the category.

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

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

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

Converting 6-monthly figures to total annual hours

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

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

- For the 0–4 year age group, a high level of input is likely to be required throughout an entire year, as intensive, ongoing input is common for the first year or two after initial diagnosis. However equipment-related interventions, such as prescribing and training in the use of new aids, would only be expected to be needed once in 12 months. Therefore, the average hours for an ideal regime in each severity category, minus the hours associated with equipment-related interventions, were added to the 6-month estimate to arrive at an annual total.
- For all other age groups a doubling of the 6-monthly figures could not be justified, as ongoing therapy over a 12-month period would not generally be expected or considered desirable. Instead, an allowance for assessment and review throughout the remainder of the year was added to the 6-month average for each age-by-severity category. This was set at 6.7%, which was the proportion of intervention hours spent on assessment and review in the ideal regimes, averaged across all case stories and replicates.

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

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

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

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

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

8.5 Costing the therapy regimes

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

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

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

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

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

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

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

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

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

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

- It is assumed that clients receiving equivalent to between the 25% regime and 75% regime receive, on average, equivalent to 50% of the ideal regime; that is, two-thirds of the 75% regime. Therefore, an additional one-third of the cost of the relevant 75% regime would be required to meet their needs (Table 8.9).
- It is assumed that all clients receiving equivalent to the 25% regime or less receive equivalent to 25% of the ideal regime; that is, one-third of the 75% regime (this assumption is conservative, as some clients in this group are likely to be receiving less). Therefore, an additional two-thirds of the cost of the relevant 75% regime would be required to meet their needs (Table 8.10).

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

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

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

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

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

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

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

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

- Population data analysis showed that slightly more than half of all people with CP and like disabilities had severe disability, which in the context of the archetypal cases was defined as always needing help in at least one core activity, as well as needing help or using aids in at least two core activities (Table A8.4). For the purposes of calculating a weighted average cost per therapy regime, the split between mild/moderate and severe disability was regarded as being equal in all age groups. The average of the annual costs associated with mild/ moderate and severe disability case stories (Table 8.8) was then averaged within each age group.
- The age distribution of people with CP and like disabilities was shown in Chapter 4 (Table 4.1). Multiplying the annual cost per age group by the percentage of people with CP and like disabilities in each age group, and summing the total, provides a weighted average annual cost of a 75% therapy regime. This equals approximately $13,900 per client (Table 8.11).
- The average annual cost per client of meeting unmet need for clients receiving therapy equivalent to between 25% and 75% of the ideal regime is 1/3 of $13,900, or $4,630.
- The average annual cost per client of meeting unmet need for clients receiving therapy equivalent to the 25% regime or less is 2/3 of $13,900, or $9,270.

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

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

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

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

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

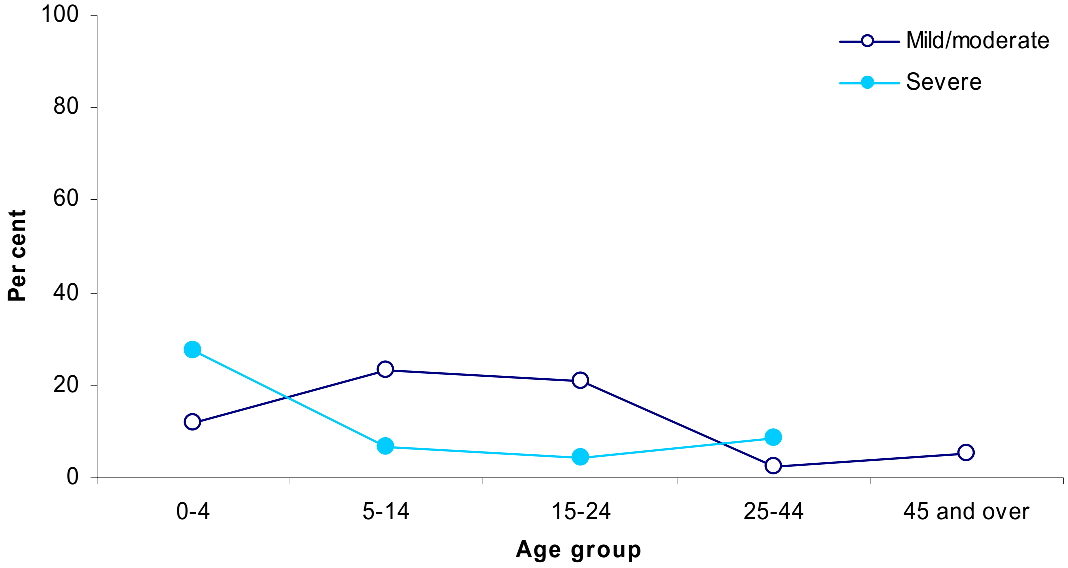
8.6 Therapists' estimates of unmet need among clients

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

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

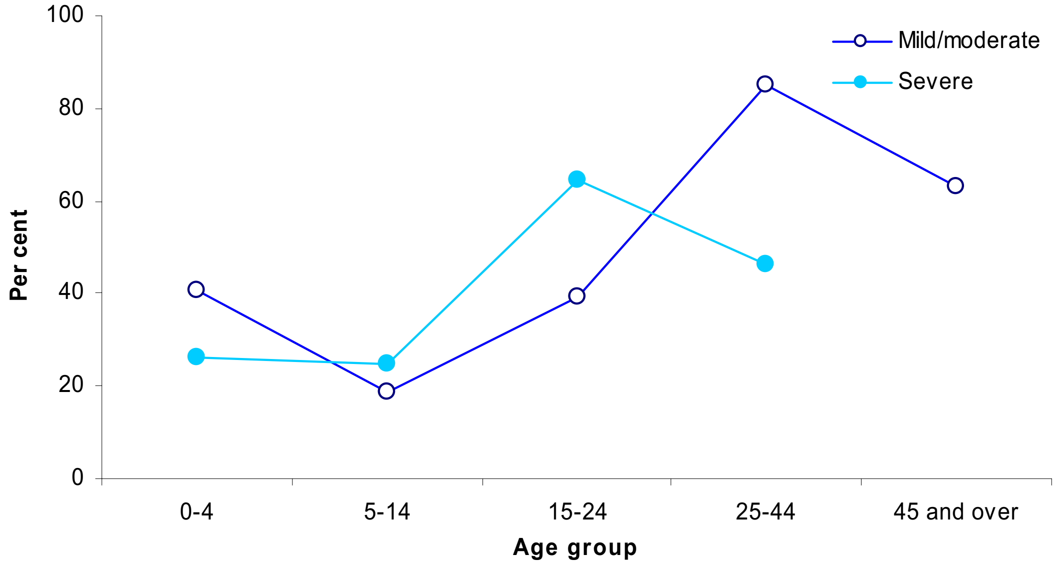
This set of estimates was given separately for the 'average' and the 'additional needs' case story in each category. Further, for each case story this set of estimates was given separately for metropolitan and non-metropolitan areas. That is, within each archetypal cases category, each group produced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

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



Source: Table 8.11

Figure 8.6: Clients receiving equivalent to the 75% regime, or more



Source: Table 8.11

Figure 8.7: Clients receiving equivalent to the 25% regime, or less

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

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

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

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

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

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

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

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

8.7 Equipment issues

Equipment-related therapy interventions

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

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

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

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

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

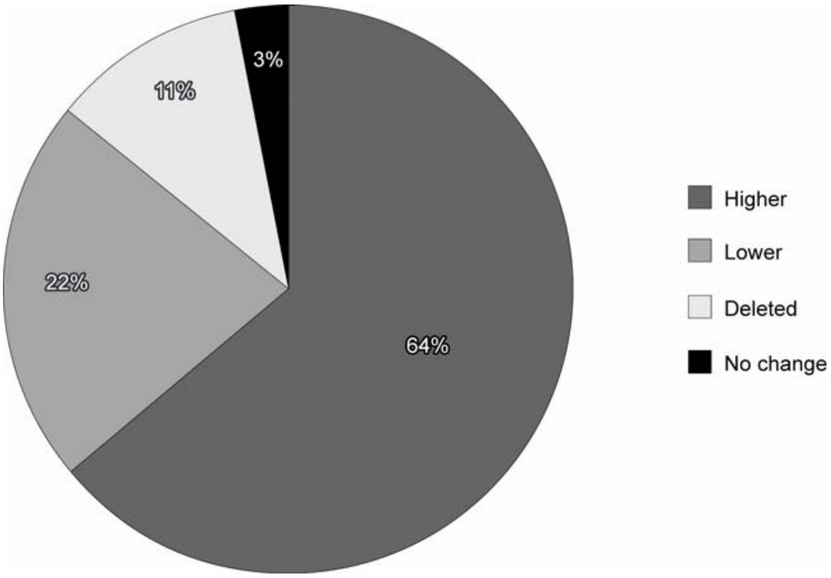


Figure 8.8: Change in the relative contribution of equipment-related interventions to total therapy hours from ideal to 25% regimes

Costing issues

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

- An individual's need for equipment in a given 6-month period is not necessarily predictive of their need for equipment over a longer time frame. Often a large investment in equipment is needed at particular times, such as around transition points, then little else may be required for several years other than maintenance and repairs. Home modifications and the purchase/modification of vans are particularly high costs that seldom recur.
- Assumptions about replacement of items in ideal regimes differed between groups. While therapists were instructed to list only those new items that would need to be purchased, some groups included replacement of some equipment items already owned by the client, to account for growth or in anticipation of adulthood, when funding eligibility changes.
- The equipment lists were not modified in line with the reduced resources regimes, therefore it is not valid to apply therapists' estimates of unmet need (that is, the percentage of clients in each age by severity category who receive less than 25% of the ideal regime, and so on) to the purchase of equipment. Clients who receive less than 25% of the ideal regime do not necessarily receive equipment worth less than 25% of the cost of all equipment prescribed.

Equipment items prescribed for archetypal cases

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

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

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

8.8 Discussion

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

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

- Therapists were provided with detailed instructions about what constitutes an ideal regime (see Section 8.2), including the stipulation that at least one member of the group must have known a client who received a level of service equivalent to the ideal regime. This ensured that the ideal regimes are deliverable in practice.
- The 75% regimes were used as the basis for calculating the cost of fully meeting need (Sections 8.5 and 9.3). Using these 'practical ideal' regimes as the benchmarks of met need is typical of the conservative approach used throughout the methodology.
- Ideal and reduced resources regimes were developed by at least two independent groups in different states for each case story. Despite different experiences of therapy funding and service delivery between states, the total hours associated with ideal regimes are of similar magnitude.

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

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

- Comparison of the case stories with data on CSTDA clients confirms that they can be considered representative of clients in each of the age-by-severity categories in terms of their support needs; however, there is no practical way of testing whether the case stories represent the median in terms of therapy needs within each archetypal case category.
- There is no single best practice approach to addressing the therapy needs of any given client; different professionals will inevitably make different decisions about the ideal set of interventions for a particular case story, resulting in a level of unavoidable variation in the total hours used as a basis for costing the archetypal cases.
- Total hours for the 75% regimes were high, compared with data available from two states on actual hours of therapy received (Table 6.12 and Table 6.13). On this basis, it may be argued that the ideal regimes are unrealistic. However, analysis of services received by individual clients of CPAWA in 2005 shows that some clients did in fact receive equivalent to the 75% regimes, or more (Table 8.14). Comparing these data to the therapists' estimates that, on average, only 13% of clients receive therapy equivalent to the 75% regime, or more (Table 8.12), supports the validity of the archetypal cases methodology.

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

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

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

Source: CPAWA ; archetypal cases data, Table 8.7.

While the archetypal cases are a rich and unique source of information on need and unmet need for therapy and equipment, they only provide a partial picture. In particular, they do not provide specific information on the extent to which people with CP and like disabilities access therapy and equipment from sources other than specialist, publicly supported organisations such as CP Australia agencies, although this may be partly reflected in the groups' estimates of levels of unmet need (that is, clients who access private therapy and also receive services from CP agencies may be included in therapists' estimates of the proportion of clients in the 75% and over group within each category).

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

9 Answering the main questions

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

9.1 Do therapy and equipment make a difference?

The first study objective was to:

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

What are the benefits of therapy?

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

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

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

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

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

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

- 'When [my son] has physio, OT and speech [therapy] he thrives and when he doesn't he drops back. Now he's limping a lot and only speaks to me…He doesn't like speaking to other people because they don't understand him.'
- 'When she's had intensive speech or physiotherapy she's skyrocketed. When it stopped, it's dropped away just as quickly.'
- 'I do notice my muscles are looser and without physiotherapy I notice the stiffening of my muscles.'

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

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

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

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

What are the benefits of equipment?

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

- One family added a modified bathroom to their house, allowing their teenage daughter privacy in bathing and toileting. This has given her 'a new lease on life'.
- Another family's home modifications enable their daughter to get herself to bed and use the kitchen.
- An adult with cerebral palsy gave a series of lectures at a university using a sophisticated speaking device.
- Several parents commented on the relief provided by hoists, slings and adjustable beds, without which they had experienced substantial back pain.

- 'From the computer I can access reading material because right now I have trouble turning pages. Also when I was driving I didn't have power steering, then when I deteriorated I benefited from power steering.'
- 'Equipment allows me to do the everyday things I want to do. I participate in the community—it increases the number of options, for example, a power wheelchair requires less energy than walking.'
- 'My gopher [scooter] opened up a new world…I go shopping and for coffee in my gopher.'
- 'Without these [powerchair, hoist and sling, incontinence aids, computer]…I wouldn't have a quality of life.'

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

The effects of provision of therapy and equipment

The third study objective was to:

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

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

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

> Equipment and therapy can have a flow-on effect to the family and the community…It has the potential to reduce medical complications and facilitate more time in the community…[There will be] less cost to the community because there will be fewer hospital admissions.
>
> [Therapy] has a flow-on effect to the family and to the community.
>
> [Therapy can result in] less burden on the hospital system, [clients] can learn to write, read and be employed.

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

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

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

- One child required a wheelchair with appropriate seating to help cope with aspiration and swallowing problems. Medical complications developed while on the waiting list. '[The child] ended up with a gastrostomy [tube] instead of a wheelchair.'
- Another child needed a few hundred dollars of modifications made to their wheelchair. The modifications did not occur and within 18 months the child had developed deformities requiring surgery and a new wheelchair.
- A child went without AFOs (ankle foot orthoses) for a year while on a surgery waiting list, having outgrown her old AFOs. She could not stand or put weight on her legs during this time, exacerbating her osteoporosis. She subsequently broke her leg.

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

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

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

The second study objective was to:

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

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

Archetypal cases

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

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

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

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

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

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

Focus groups

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

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

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

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

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

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

- ‘[There is a] need for direct and indirect forms of therapy…The unmet need is in the direct form of therapy, which is affected by the number of therapists and learning skills.’
- ‘[There is] almost no room for hands-on therapy for adults…as they age, they probably need more hands-on therapy.’

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

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

- ‘We’d like to provide therapy rather than chase up money’.
- ‘Therapy is way down the list of priorities as a therapist.’

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

- ‘Getting a ride can take half a day for 30–40 minutes of therapy.’
- ‘It takes a long time to get to therapy and back—that takes up two days a week and I can’t do anything else. It has an impact on my family.’

Population data on participation and need for assistance

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

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

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

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

CP agency data on waiting lists

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

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

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

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

Overall picture of the nature of unmet need

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

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

9.3 The extent of met and unmet needs for therapy

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

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

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

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

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

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

- 4,600 received informal assistance only (Table 7.10); these are non-clients. Their needs are difficult to quantify and therefore are not included in the estimation here, but are considered in the discussion below.
- 4,700 received a mix of formal and informal assistance (Table 7.10); these are clients, although the population data do not tell us of what agencies.

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

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

There are three main pieces of evidence to support this:

- Compared with other CSTDA service users, CP agency clients have relatively high support needs (Table 6.4), and a much higher percentage of them use community support services, particularly therapy (Table 6.6). This suggests a relationship between need for help with core activities and need for therapy.
- Data provided by CPAWA indicate a strong relationship between support needs and FIM scores, which are used by some CP agencies to indicate need for therapy—this suggests that therapy professionals consider support needs a reliable indicator of need for therapy.
- In the archetypal cases, therapist groups developed more intensive therapy and equipment regimes for case stories of clients with more severe disability (characterised by higher support needs in self-care, mobility and communication)—this suggests that, in general, professionals regard people with higher support needs as likely to need more therapy. A study of therapy delivered to children with disabilities in Australia reported a similar broad finding (Dyson, 2000).

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

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

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

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

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

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

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

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

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

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

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

Summary of assumptions

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

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

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

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

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

Method 2: Using population data together with archetypal cases data

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

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

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

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

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

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

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

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

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

Summary of assumptions

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

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

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

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

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

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

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

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

  In CSTDA terms, archetypal cases 'severe' case stories can be identified as:
  - always needs help in at least one core area, and
  - needs help or uses aids in at least two core activity areas.

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

- Therapists' estimates of levels of unmet need (for each category, by metropolitan / non-metropolitan—see Table 8.12) were applied to these CSTDA numbers, to estimate the number of people in each category receiving therapy equivalent to:
  - between the 25% regime and 75% regime
  - the 25% regime or less
- These estimates were multiplied by the appropriate cost figure for that category (that is, the cost of meeting unmet needs for a person receiving equivalent to between the 25% regime and 75% regime, and equivalent to the 25% regime or less, respectively—Tables 8.10 and 8.11)
- The resulting dollar amounts were summed across all nine categories.

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

Summary of assumptions

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

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

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

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

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

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

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

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

(continued)

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

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

Discussion

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

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

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

Non-clients

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

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

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

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

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

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

Discussion of assumptions and overall effect on estimates

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

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

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

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

Box 9.1: Discussion of estimation errors and confidence

Like any population sampling survey data, the ABS 2003 SDAC data are subject to sampling error. As a general guide, estimates of less than 2,100 have an associated relative standard error (RSE) of 50% or more and estimates of less than 10,400 have an associated RSE between 25% and 50%.

For example, the standard error of the estimate of 4,800 clients with partly met need is 1,690 (an RSE of 35%). Therefore, there are about two chances in three that the actual number of people in this category was within the range of 3,100 to 6,500 and about 19 chances in 20 that it was within the range 1,500 to 8,100. Applying this range to the estimates that rely on the estimate of 4,800 clients produces the following corresponding ranges:

- *Method 1: $19.9m to $41.3m*
- *Method 2: $13.7m to $28.5m*

For method 3 it is not possible to estimate a confidence interval. Both methods 2 and 3 are affected by variation inherent in the archetypal cases data (as discussed in Sections 8.4 and 8.6).

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

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

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

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

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

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

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

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

Notes

1. Annual unmet need for equipment in NSW was calculated by averaging the cost of equipment requests made in 2004–05 and 2005–06 that remained unfunded at the end of the respective financial years. WA data represent unfunded requests made in the 2005–06 financial year, as of 20 June 2006. SA data represent the cost of unfunded requests to the Independent Living Equipment Program made between June and August 2006, and therefore are likely to underestimate the cost of unmet need over a full year.
2. The estimated national annual cost of unmet need for equipment was calculated by multiplying the average 'cost per client' in each state by the number of CP agency clients nationally.
3. SA data exclude unmet need for equipment among people aged over 18 years.

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

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

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

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

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

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

9.5 Conclusions

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

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

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

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

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

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

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

Appendix A Tables

Table A1.1: Main organisations making up CP Australia: client base, client numbers, services and funding details, 2004-05

Organisation	Client base	No. clients[(a)]	Services/initiatives	Income $'000	% govt. funding	Expenditure $'000
Cerebral Palsy League of Queensland	Children and adults with cerebral palsy and related disabilities.	2,765	Therapy, respite, accommodation, adult day services, employment services, business services, technology services, mobility and seating services, specialist medical clinics, consultancy and advisory services, professional development and training, disability awareness programs, information services, fundraising, volunteer program, equipment service and research programs.	34,318	85	34,000
Cerebral Palsy Tasmania	Children and adults with disabilities, particularly those with cerebral palsy.	871	Employment, equipment and technology loan (school age), financial support and transport (school age).	1,133	42	907
Cerebral Palsy Association of Western Australia	Children and adults with cerebral palsy and similar physical disabilities.	930	Therapy, respite, accommodation, adult day services, employment services, business services, technology services, mobility and seating services, specialist medical clinics, consultancy and advisory services, professional development and training, disability awareness programs, advocacy, information services, fundraising, volunteer program, equipment services, and research programs.	27,000	72	27,000
Community Access Services, SA [Spastic Centres of South Australia]	Adults with severe and multiple disabilities.	300	Adult day services (community access), fundraising, disability awareness raising and volunteer program.	5,500	77	5,450
Community Accommodation and Respite Agency, SA [Spastic Centres of SA]	Children and adults with severe and multiple disabilities.	500	Accommodation and respite services, independent living skills, disability health care support services and volunteer program.	13,000	83	13,000
Cootharinga Society of North Queensland	Predominantly adults with physical disabilities, particularly cerebral palsy.	287	Accommodation, individual support, family support, community access, therapy, advocacy, rehabilitation and technology service, resource and information centre, consultancy and advisory service, professional development and training, fundraising and volunteer program.	5,713	88	5,561

(continued)

Table A1.1 (continued): Main organisations making up CP Australia: client base, client numbers, services and funding details, 2004-05

Organisation	Client base	No. clients[a]	Services/initiatives	Income $'000	% govt. funding	Expenditure $'000
Leveda, SA	People with disability and complex support needs	90	Accommodation, respite and community support.	4,621	82	4,620
Novita Children's Services, SA	Children 0-18 years with a permanent disability associated with a physical impairment.	1300 (3371 NovitaTech)	Therapy, family support, resource loan service, nutrition and dietetics, inclusion support, brain injury support service, family support, specialist medical clinics and clinical research. NovitaTech—technology, mobility and seating, orthotics, engineering, research and service development.	22,918	44	20,302
Scope, Vic	Children and adults with physical and multiple disabilities.	4,500	Therapy, respite, accommodation, adult day services, employment services, business services, leisure programs, consultancy and advisory services, professional development and training, disability awareness programs, communication resource centre, information services, community capacity building, research program, fundraising, and volunteer program.	58,142	74	53,800
The Spastic Centre, NSW	Children and adults with cerebral palsy and allied disorders. Children 0-18 with complex and significant needs (in selected regions of NSW).	3,000	Therapy, respite, accommodation, adult day services, employment services, business services, technology services, mobility and seating services, dental program, specialist medical clinics, consultancy and advisory services, professional development and training, disability awareness programs, information services, fundraising, volunteer program, conductive education, equipment services, aquatic programs, family support, CP Helpline, CP Foundation, international development and exchange program, CP Register and research programs.	56,431	56	55,299
Yooralla, Vic	Children and adults with a disability acquired from birth, accident, ill health or age.	3,503	Therapy, respite, accommodation, adult day services, employment services, leisure programs, mobility services, consultancy and advisory services, professional development and training, information services, fundraising, volunteer program, conductive education, and equipment services.	61,385	67	61,778
All		**about 20,000**		**290,000**	**70**	**$282,000**

(a) Client numbers are estimates for some organisations. Clients of NovitaTech may also access Novita Children's Services.

Table A4.1: Preliminary estimates of CP-like conditions using the 2003 SDAC Confidentialised Unit Record File

Condition[a]	With a condition	With a disability	With a disability and – aged under 45 years with a given condition, or – aged 45 or over with a given main disabling condition which occurred before age 45[b]
Head injury/acquired brain damage	816,500	438,300	174,600
Other diseases of the nervous system	197,300	172,500	50,900
Congenital disorders	106,200	96,300	74,200

(a) See Appendix Table A4.2 for detailed code.

(b) Excludes people aged 45 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.

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

Table A6.1: CP agency service users of CSTDA-funded services, age and age group by sex, 2003–04

Age (years)	Males	Females	Not stated	Total	Per cent
0	10	4	—	14	0.1
1	58	47	—	105	1.1
2	114	84	—	198	2.1
3	124	104	—	228	2.4
4	142	117	—	259	2.8
5	211	146	—	357	3.8
6	247	169	—	416	4.4
7	202	155	—	357	3.8
8	234	147	—	381	4.1
9	219	164	—	383	4.1
10	181	125	—	306	3.3
11	190	142	—	332	3.5
12	192	129	1	322	3.4
13	172	128	—	300	3.2
14	168	118	—	286	3.0
15	167	112	—	279	3.0
16	156	101	—	257	2.7
17	136	105	—	241	2.6
18	128	107	—	235	2.5
19	104	89	—	193	2.1
20–24	363	340	1	704	7.5
25–29	312	283	—	595	6.3
30–34	280	285	3	568	6.0
35–39	232	203	1	436	4.6
40–44	178	205	3	386	4.1
45–59	477	405	6	888	9.4
60+	163	199	—	362	3.9
Not stated	5	5	—	10	0.1
Total	**5,165**	**4,218**	**15**	**9,398**	**100.0**
Per cent	**55.0**	**44.9**	**0.2**	**100.0**	

Note: 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.

Table A6.2: All other service users of CSTDA-funded services, age and age group by sex, 2003–04

Age (years)	Male	Female	Not stated	Total	Per cent
0	201	172	3	376	0.2
1	449	411	1	861	0.5
2	786	497	3	1,286	0.7
3	1,375	756	—	2,131	1.2
4	1,938	944	3	2,885	1.6
5	2,031	893	1	2,925	1.6
6	1,536	729	1	2,266	1.3
7	1,282	650	1	1,933	1.1
8	1,278	667	2	1,947	1.1
9	1,330	688	2	2,020	1.1
10	1,340	700	—	2,040	1.1
11	1,298	721	2	2,021	1.1
12	1,272	708	2	1,982	1.1
13	1,254	750	1	2,005	1.1
14	1,291	670	1	1,962	1.1
15	1,325	756	—	2,081	1.2
16	1,724	893	1	2,618	1.5
17	2,047	1,091	—	3,138	1.8
18	2,375	1,523	1	3,899	2.2
19	2,798	1,688	—	4,486	2.5
20–24	11,668	7,505	5	19,178	10.7
25–29	8,905	5,779	6	14,690	8.2
30–34	9,155	6,032	7	15,194	8.5
35–39	8,567	5,900	8	14,475	8.1
40–44	8,488	6,272	4	14,764	8.3
45–59	17,584	14,024	24	31,632	17.7
60+	6,857	8,405	9	15,271	8.6
Not stated	5,458	2,811	73	8,342	4.7
Total	**105,612**	**72,635**	**161**	**178,408**	**100.0**
Per cent	**59.1**	**40.8**	**0.1**	**100.0**	

Note: 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.

Table A6.3 Primary disability group, and all significant disability groups, CP agency service users and all other service users, 2003–04

Disability group	Primary disability group reported	% of all service users	All significant disability groups reported, including primary	% of all service users
CP agency service user				
Intellectual	2,660	28.3	5,618	59.8
Psychiatric	29	0.3	382	4.1
Sensory	182	1.9	4,339	46.2
Physical	5,296	56.4	7,269	77.3
ABI	378	4.0	799	8.5
Not stated	853	9.1	n.a.	n.a
Total	**9,398**	**100.0**		
All other service users				
Intellectual	92,717	52.0	100,897	56.6
Psychiatric	15,530	8.7	24,371	13.7
Sensory	16,318	9.1	41,287	23.1
Physical	29,570	16.6	54,233	30.4
ABI	7,539	4.2	10,703	6.0
Not stated	16,734	9.4	n.a.	n.a
Total	**178,408**	**100.0**		

Note: 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.

Table A6.4: Life area by frequency of support or assistance needed, CP agency service users and all other service users, 2003–04

Frequency of support needed	Always or unable to do		Sometimes		None but uses aids		None		Not applicable		Not stated/ not collected		Total	
	No.	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**
CP agency service users														
Activities of daily living (ADL)														
Self-care	4,252	45.2	2,171	23.1	169	1.8	747	7.9	—	—	2,059	21.9	9,398	100.0
Mobility	3,469	36.9	2,290	24.4	605	6.4	1,239	13.2	—	—	1,795	19.1	9,398	100.0
Communication	3,281	34.9	2,245	23.9	214	2.3	1,866	19.9	—	—	1,792	19.1	9,398	100.0
All ADL	*4,788*	*50.9*	*2,151*	*22.9*	*213*	*2.3*	*491*	*5.2*	—	—	*1,755*	*18.7*	*9,398*	*100.0*
Activities of independent living (AIL)														
Interpersonal interactions[(a)]	3,131	33.3	2,757	29.3	156	1.7	1,260	13.4	—	—	2,094	22.3	9,398	100.0
Learning[(b)]	3,333	35.5	2,555	27.2	200	2.1	771	8.2	423	4.5	2,116	22.5	9,398	100.0
Domestic life	3,012	32	1,350	14.4	93	1	281	3	1,860	19.8	2,802	29.8	9,398	100.0
All AIL	*4,524*	*48.1*	*2,267*	*24.1*	*118*	*1.3*	*430*	*4.6*	*204*	*2.2*	*1,855*	*19.7*	*9,398*	*100.0*
Activities of education, work and community living (AWEC)														
Education	3,635	38.7	2,318	24.7	216	2.3	670	7.1	430	4.6	2,129	22.7	9,398	100.0
Community (civic) and economic life	3,818	40.6	2,161	23	158	1.7	651	6.9	432	4.6	2,178	23.2	9,398	100.0
Working	3,221	34.3	967	10.3	95	1	271	2.9	1,948	20.7	2,896	30.8	9,398	100.0
All AWEC	*4,721*	*50.2*	*1,711*	*18.2*	*113*	*1.2*	*351*	*3.7*	*603*	*6.4*	*1,899*	*20.2*	*9,398*	*100.0*

(continued)

Table A6.4 (continued): Life area by frequency of support or assistance needed, CP agency service users and all other service users, 2003–04

Frequency of support needed	Always or unable to do		Sometimes		None but uses aids		None		Not applicable		Not stated/ not collected		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
All other service users														
Activities of daily living (ADL)														
Self-care	25,876	14.5	42,549	23.8	4,861	2.7	55,361	31.0	—	—	49,761	27.9	178,408	100.0
Mobility	21,708	12.2	38,328	21.5	7,662	4.3	61,897	34.7	—	—	48,813	27.4	178,408	100.0
Communication	22,995	12.9	53,053	29.7	4,294	2.4	49,738	27.9	—	—	48,328	27.1	178,408	100.0
All ADL	*34,018*	*19.1*	*61,285*	*34.4*	*5,891*	*3.3*	*29,313*	*16.4*	—	—	*47,901*	*26.8*	*178,408*	*100.0*
Activities of independent living (AIL)														
Interpersonal interactions[(a)]	26,789	15.0	67,139	37.6	3,512	2.0	31,106	17.4	—	—	49,862	27.9	178,408	100.0
Learning[(b)]	29,616	16.6	67,606	37.9	4,349	2.4	24,228	13.6	7,474	4.2	45,135	25.3	178,408	100.0
Domestic life	28,152	15.8	46,252	25.9	4,127	2.3	32,516	18.2	14,585	8.2	52,776	29.6	178,408	100.0
All AIL	*42,324*	*23.7*	*71,378*	*40.0*	*3,299*	*1.8*	*12,669*	*7.1*	*6,672*	*3.7*	*42,066*	*23.6*	*178,408*	*100.0*
Activities of education, work and community living (AWEC)														
Education	35,734	20.0	57,923	32.5	4,605	2.6	24,770	13.9	7,407	4.2	47,969	26.9	178,408	100.0
Community (civic) and economic life	32,646	18.3	54,269	30.4	4,707	2.6	30,143	16.9	7,412	4.2	49,231	27.6	178,408	100.0
Working	39,378	22.1	58,464	32.8	3,788	2.1	12,471	7.0	14,847	8.3	49,460	27.7	178,408	100.0
All AWEC	*51,965*	*29.1*	*63,030*	*35.3*	*3,660*	*2.1*	*8,189*	*4.6*	*8,501*	*4.8*	*43,063*	*24.1*	*178,408*	*100.0*

(a) The full name for the life area 'interpersonal interactions' is 'interpersonal interactions and relationships'.

(b) The full name for the life area 'learning' is 'learning, applying knowledge and general tasks and demands'.

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.
2. The frequency of support needed for a service user for each of the three broad groups (ADL, AIL and AWEC) is based on the highest support need category of the service user for that group. For example, if a service user reports 'always or unable to do' for the life area of self-care (one of the ADL areas) then that service user will be placed into the 'always or unable to do' category for ADL, regardless of their support needs for mobility or communication (the other two ADL areas). Therefore the totals for each of the broad groups (ADL, AIL and AWEC) cannot be calculated by adding totals from the three component life areas.
3. 'Not stated/not collected' includes both service users accessing only 3.02 (Recreation/holiday programs) services for whom support needs data were not collected and other service users with no response.

Table A6.5: Life area by frequency of support or assistance needed, CP agency service users and all other service users aged under 45 years, 2003–04

Frequency of support needed	Always or unable to do		Sometimes		None but uses aids		None		Not applicable		Not stated/ not collected		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
CP agency service users														
Activities of daily living (ADL)														
Self-care	3,773	46.4	1,875	23.0	114	1.4	604	7.4	—	—	1,772	21.8	8,138	100.0
Mobility	3,068	37.7	1,922	23.6	464	5.7	1,098	13.5	—	—	1,586	19.5	8,138	100.0
Communication	2,980	36.6	1,887	23.2	162	2.0	1,525	18.7	—	—	1,584	19.5	8,138	100.0
All ADL	*4,215*	*51.8*	*1,819*	*22.4*	*137*	*1.7*	*417*	*5.1*	—	—	*1,550*	*19.0*	*8,138*	*100.0*
Activities of independent living (AIL)														
Interpersonal interactions[(a)]	2,870	35.3	2,353	28.9	117	1.4	995	12.2	—	—	1,803	22.2	8,138	100.0
Learning[(b)]	2,986	36.7	2,163	26.6	147	1.8	598	7.3	423	5.2	1,821	22.4	8,138	100.0
Domestic life	2,498	30.7	1,022	12.6	49	0.6	211	2.6	1,860	22.9	2,498	30.7	8,138	100.0
All AIL	*3,975*	*48.8*	*1,936*	*23.8*	*74*	*0.9*	*378*	*4.6*	*204*	*2.5*	*1,571*	*19.3*	*8,138*	*100.0*
Activities of education, work and community living (AWEC)														
Education	3,213	39.5	2,009	24.7	170	2.1	502	6.2	430	5.3	1,814	22.3	8,138	100.0
Community (civic) and economic life	3,396	41.7	1,823	22.4	109	1.3	499	6.1	432	5.3	1,879	23.1	8,138	100.0
Working	2,616	32.1	762	9.4	60	0.7	186	2.3	1,948	23.9	2,566	31.5	8,138	100.0
All AWEC	*4,072*	*50.0*	*1,489*	*18.3*	*82*	*1.0*	*281*	*3.5*	*603*	*7.4*	*1,611*	*19.8*	*8,138*	*100.0*

(continued)

Table A6.5 (continued): Life area by frequency of support or assistance needed, CP agency service users and all other service users aged under 45 years, 2003–04

Frequency of support needed	Always or unable to do		Sometimes		None but uses aids		None		Not applicable		Not stated/ not collected		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
All other service users														
Activities of daily living (ADL)														
Self-care	19,619	15.9	31,273	25.4	2,854	2.3	40,089	32.5	—	—	29,328	23.8	123,163	100.0
Mobility	16,311	13.2	27,212	22.1	4,418	3.6	46,614	37.8	—	—	28,608	23.2	123,163	100.0
Communication	18,530	15.0	40,074	32.5	2,432	2.0	33,927	27.5	—	—	28,200	22.9	123,163	100.0
All ADL	*25,619*	*20.8*	*45,248*	*36.7*	*3,240*	*2.6*	*21,178*	*17.2*	—	—	*27,878*	*22.6*	*123,163*	*100.0*
Activities of independent living (AIL)														
Interpersonal interactions[(a)]	21,571	17.5	50,697	41.2	2,000	1.6	19,626	15.9	—	—	29,269	23.8	123,163	100.0
Learning[(b)]	22,789	18.5	51,692	42.0	2,357	1.9	14,393	11.7	1,976	1.6	29,956	24.3	123,163	100.0
Domestic life	19,330	15.7	32,575	26.4	2,354	1.9	23,048	18.7	8,406	6.8	37,450	30.4	123,163	100.0
All AIL	*31,635*	*25.7*	*53,513*	*43.4*	*1,785*	*1.4*	*7,836*	*6.4*	*494*	*0.4*	*27,900*	*22.7*	*123,163*	*100.0*
Activities of education, work and community living (AWEC)														
Education	26,511	21.5	45,512	37.0	2,544	2.1	14,888	12.1	1,909	1.5	31,799	25.8	123,163	100.0
Community (civic) and economic life	24,789	20.1	40,497	32.9	2,560	2.1	20,111	16.3	1,914	1.6	33,292	27.0	123,163	100.0
Working	26,610	21.6	44,319	36.0	2,091	1.7	7,100	5.8	8,668	7.0	34,375	27.9	123,163	100.0
All AWEC	*37,253*	*30.2*	*48,223*	*39.2*	*1,820*	*1.5*	*4,701*	*3.8*	*2,322*	*1.9*	*28,844*	*23.4*	*123,163*	*100.0*

(a) The full name for the life area 'interpersonal interactions' is 'interpersonal interactions and relationships'.

(b) The full name for the life area 'learning' is 'learning, applying knowledge and general tasks and demands'.

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.
2. The frequency of support needed for a service user for each of the three broad groups (ADL, AIL and AWEC) is based on the highest support need category of the service user for that group. For example, if a service user reports 'always or unable to do' for the life area of self-care (one of the ADL areas) then that service user will be placed into the 'always or unable to do' category for ADL, regardless of their support needs for mobility or communication (the other two ADL areas). Therefore the totals for each of the broad groups (ADL, AIL and AWEC) cannot be calculated by adding totals from the three component life areas.
3. 'Not stated/not collected' includes both service users accessing only 3.02 (Recreation/holiday programs) services for whom support needs data were not collected and other service users with no response.

Table A6.6: Presence of an informal carer by age group, CP agency service users and all other service users, 2003–04

	CP agency service users		All other service users	
Age group	**No.**	**% of users**	**No.**	**% of users**
0–4	703	90.1	6,401	96.6
5–9	1,593	89.7	8,869	95.7
10–14	1,289	87.2	7,262	93.8
15-19	1,021	87.9	8,000	62.1
20–24	535	80.5	8,394	50.1
25–29	391	69.9	5,907	45.7
30–34	277	56.8	5,402	41.7
35–39	216	52.8	4,896	39.3
40–44	184	50.3	4,498	35.7
45–59	377	45.2	8,638	32.4
60+	101	32.5	3,359	31.3
Total [(a)]	**6,690**	**75.7**	**71,670**	**50.6**

(a) Total includes age not stated (3 for CP agency users and 44 for other service users).

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. Column totals may not be the sum of components since individuals may have accessed services in more than one service group over the 12-month period. Service user data were not collected for all CSTDA service types.
2. Table excludes 'not stated' responses for this data item (564 for agency users and 36,744 for all other users). Percentage of users is calculated based on number of users who reported carer information.

Table A8.1: Factors that influence need for therapy and relevant data items from national data sources

Factors that influence need for therapy	Commonwealth–State/Territory Disability Agreement National Minimum Data Set	ABS Survey of Disability, Ageing and Carers
Demographic factors		
Age	Date of birth	Date of birth
Sex	Sex	Sex
Geographic location (metropolitan, rural etc.)	Postcode of residence	ARIA; state/territory of usual residence
Cultural and linguistic background	Country of birth; Indigenous status; Interpreter services required (for language other than English)	Country of birth; How personal interview was obtained (e.g. in language other than English)
Health, disability, and support needs factors		
Disability severity Independence in activities of daily living Areas of need for assistance Potential health and safety issues Presence of challenging behaviour Multiple disabilities (e.g. intellectual, sensory) Physical impairment and associated musculoskeletal factors Associated medical issues (e.g. epilepsy, recurrent respiratory infections relating to aspiration) Recent diagnosis (in last 12 months) Potential for improvement Progress over past 12 months Presence of a deteriorating condition	Need for assistance in nine life areas (including self-care, mobility and communication) Disability group (primary and other) Clinical measures (e.g. FIM, GMFCS) and diagnosis available from some CP agency databases	Impairments and limitations (i.e. survey screening questions) Long term health conditions Difficulty and need for assistance with various activities (including self-care, mobility and communication) Schooling and employment restrictions Whether uses aids or equipment; types of activities for which aids or equipment used, and types of equipment Requirements to enable workforce participation Ability to look after self at home when other household members are away Type of difficulty experienced at school (includes fitting in socially) Whether main condition is expected to improve over the next 2 years
Environmental factors		
Family functioning Living situation Availability of informal care Level of support available in school or workplace Participation in employment or day program Participation in recreational/social activities Proactivity of carers Physical environment	Living arrangements (alone, with family, with others) Residential setting Carer arrangements (including information on carer's residency status and relationship to service user) Service type (includes day programs and employment services) Main source of income (16 yrs and over; includes compensation payments)	Type of special dwelling Family type Household type Type of assistance received in broad activity areas (includes informal care) Unmet need for informal care with specified activities School attendance; reason for not attending school; type of difficulty experienced at school; schooling restriction status (includes uses special assistance, equipment or arrangements at school)

(continued)

Table A8.1 (continued): Factors that influence need for therapy and relevant data items from national data sources

Factors that influence need for therapy	Commonwealth–State/Territory Disability Agreement National Minimum Data Set	ABS Survey of Disability, Ageing and Carers
Environmental factors (continued)		
Expectations (of person and family) Potential to access mainstream education Family indicators e.g. low socio-economic status, limited access to education, single parent family, little informal support, recently divorced Presence of a sibling with a disability Parental health issues		Type of support or special arrangements provided at school or institution; whether attends special school or classes or receives special support; level and type of non-school education restriction Employment restriction (type and severity); requirements to enable workforce participation; labour force status Participation in social/community or cultural/leisure activities in past 3 or 12 months; frequency of attendance at supervised activity program Private dwelling structure; whether dwelling has been modified because of condition Family type; household type; housing tenure; total weekly equivalised cash income (household); total weekly cash income (household, income unit, person); pensions, benefits and allowances received Number of persons with disability in family/household/income unit Whether family with children has a parent with a disability
Transitional factors		
Post-surgery Life stage transitions (e.g. into adolescence) Moving out of family home Transition to school or from primary to high school Transition into workforce or higher education Transition into retirement		House moves person made because of age or condition; year in which last house move

Table A8.2: Summary of key factors in case stories, categorised according to the ICF framework

Case story	Personal factors	Health condition	Body functions and structures	Activities	Participation	Environmental factors	Support needs	Current Interventions
1A: Liam 0–4 years, mild/moderate disability	Male 2 years	*Diagnosis* Left spastic hemiparesis *History* Born at 28wk Neonatal brain haemorrhage	Recent growth spurt—improved walking, leg tone Can grasp with left hand GOALS Parents educated about casting, AFO use Mother educated about play positions to stretch left leg	Able to handle toys Expressive and receptive language skills slightly below average; developing well Vocab of ~30 words GOALS Stabilise bowl with left hand while eating Improve range of vocab, use two-word phrases		Receiving CP Australia services since diagnosis (9 months) 2 older siblings aged 5 and 8 Mother actively encourages communication skill development	Self-care: Age appropriate skills, some difficulty holding a cup Mobility: Will use aids in future (AFOs) Communication: Slight delay	*Therapy* Regular speech therapy, physiotherapy, and occupational therapy *Equipment* Needs AFO
1B: Jack 0–4 years, mild/moderate disability	Male 3 years Twin	*Diagnosis* Primary spastic diplegia *History* Born at 32 wk Cerebral haemorrhage	Spastic diplegia Mild involvement in left arm Lower limb hypertonia	‘Significant progress’ over 2 years Age appropriate language development GOALS Walk 10 metres independently in walker with verbal prompting Independence in toileting Develop fine motor skills, using both arms/hands in play		Receiving CP Australia services for 2 years Sibling relationship issues Father works long hours, extended family interstate Parental marriage difficulties GOALS Social work support for mother regarding children’s behaviour, relationship strain. Respite for parents	Self-care: Needs help toileting Mobility: Trialled walking aids Communication: No limitations	*Therapy* Physiotherapy, occupational therapy *Equipment* AFOs (recent) Applied for Kaye walker funding

(continued)

Table A8.2 (continued): Summary of key factors in case stories, categorised according to the ICF framework

Case story	Personal factors	Health condition	Body functions and structures	Activities	Participation	Environmental factors	Support needs	Current Interventions
2A: Sarah 0–4 years, severe disability	Female 3 years 9 months	*Diagnosis* Spastic quadriplegia cerebral palsy, epilepsy, developmental delay, microcephaly *History* Neonatal meningitis	Normal vision Moderate hearing loss ? GOALS Wear AFOs for 15 minutes while in standing frame Hold head in midline for 15 seconds while in insert	Difficulty swallowing Communicates with family using eyes, face, body movements and vocalisations GOALS Hold her head up while sitting in insert Exposure to switching to develop communication skills	Starting kindergarten in 2007 GOALS Investigate kindergarten options Apply for wheelchair	Receiving CP Australia services for 3 years (physiotherapy, occupational therapy, speech therapy) 10 year old sister Professional parents	Self-care: Always needs help eating and drinking Mobility: Uses aids Communication: Some difficulty/ delay (uses facial expressions, body movements, vocalisations)	*Therapy* Speech therapy, physiotherapy, occupational therapy, private physiotherapy *Equipment* postural insert and stroller Prone stander Fixed AFO Bath seat
2B: Ria 0–4 years, severe disability	Female 19 months New diagnosis	*Diagnosis* Spastic quadriplegia *History* Born at 39 weeks Difficult birth, foetal distress Difficult sleeper Irritable	'Floppy' infant Very poor head control Scissors Plantarflexed at ankles increased spasticity in lower limbs GOALS Information about cerebral palsy and emotional support to family	'Slow developer' Not yet rolling Requires full support for sitting Difficult sleeper, irritable GOALS Assess for equip to aid functioning and participation Ria's parents to be educated about positioning	Beginning to socialise Very aware of surroundings	Two older half-brothers aged 12 and 23 Recently moved from country to metropolitan area to access CP services	Self-care: Totally dependent Mobility: Needs support sitting, not rolling; being assessed for equip Communication: Some difficulty/ delay—beginning to babble	GOALS Family meeting to determine goals

(continued)

Table A8.2 (continued): Summary of key factors in case stories, categorised according to the ICF framework

Case story	Personal factors	Health condition	Body functions and structures	Activities	Participation	Environmental factors	Support needs	Current Interventions
3A: Ryan 5–14 years, mild/moderate disability	Male 6 years	*Diagnosis* Right hemiplegia *History* Elective caesarean 38 weeks	'Fisted hand' Spasticity in arm and leg GOALS Information on botox and follow-up to be provided to family	Sat at 9 months First words at 15 months Walked at 22 months Delay in receptive and expressive language—not well understood by those who don't know him well GOALS Independence in toileting at school Eat dinner with fork Increased vocabulary and length of utterance	Completed pre-primary; will start full-time school Socialises with peers Afraid to participate in outdoor activities at school GOALS Confidence in using playground equip at school and park Clearer speech to communicate with people who don't know him well	Receiving CP Australia services since diagnosis 10 year old sibling Parents run own business Parents proactive and involved	Self-care: Always needs help toileting; uses aids (splints) Mobility: Uses orthoses Communication: Some difficulty being understood	*Therapy* Physiotherapy, occupational therapy, speech therapy, point percussion, swimming, horse riding Waiting for assessment for botox *Equipment* Second skin hand and arm splint Right AFO
3B: Maya 5–14 years, mild/moderate disability	Female 11 years	*Diagnosis* Spastic diplegia (19 months) *History* Unknown aetiology	Some balance difficulties Recent surgery, botox treatment on legs due to tightness, contractures GOALS Therapeutic and emotional support following surgery	Uses a K walker, prefers to crawl at home GOALS Walk 500 metres in K walker without tiring More independence in dressing	Attends local primary school Educational aide 2 days/week Participates well in class School leader	Receiving services from CP Australia since diagnosis Both parents very involved in care Strong family support network Popular, bright student	Self-care: Needs some help with dressing, toileting, bathing Mobility: Uses aids (AFOs, K walker, manual wheelchair) Communication: No limitations	*Equipment* Home modifications—bathroom Shower chair, manual wheelchair (used for long distances only), Fixed AFOs, Kaye walker

(continued)

Table A8.2 (continued): Summary of key factors in case stories, categorised according to the ICF framework

Case story	Personal factors	Health condition	Body functions and structures	Activities	Participation	Environmental factors	Support needs	Current Interventions
4A: Ali 5–14 years, severe disability	Male 10 years	*Diagnosis* Mixed quadriparesis, epilepsy and visual impairment *History* Diagnosis resulted from motor vehicle accident at 2 years of age.	Severe physical impairment in upper and lower limbs Swallowing difficulties—eats pureed food Becoming heavier and more difficult to transfer GOALS Manual handling plan update at school and home Equipment to ensure safe and comfortable positioning in all environments	Requires supervision and assistance for all meals Uses a Hart Walker with assistance GOALS Walk in his walker at school twice a week GOALS Continue to indicate needs/wants interacting with peers and teachers at school	Attends Education Support School Modified curriculum Educational assistant	Father died in the accident Mother sole carer Parents migrated from Mozambique before his birth	Self-care: Completely dependent for all aspects Mobility: Uses aids (manual wheelchair pushed by others); needs two people to lift for transfers Communication: Non-verbal	*Therapy* Physiotherapy, occupational therapy, speech pathology (provided through school) *Equipment* Manual wheelchair, David Hart walker, fixed AFOs

(continued)

Table A8.2 (continued): Summary of key factors in case stories, categorised according to the ICF framework

Case story	Personal factors	Health condition	Body functions and structures	Activities	Participation	Environmental factors	Support needs	Current Interventions
4B: Alex 5–14 years, severe disability	Male 13 years	*Diagnosis* Athetoid CP, epilepsy *History* Born at 28 weeks, intensive care for several weeks Takes epilepsy medication	Fluctuating muscle tone Involuntary body movements Initiates movement using extensor patterning Continent	Family work to maintain standing skills Age-appropriate receptive communication skills Indicates yes/no with his head; difficult for strangers to understand Understands switching and scanning; difficulty using computers due to involuntary movement GOALS Improve switching accuracy with right knee	Transitioning to high school GOALS Support teachers in increased access to curriculum Assess new school environment for access issues Provide Alex and family with information to aid transition to high school	Receiving CP agency services for 9 years 10 year old brother Father works nights as a chef Cognitively bright	Self-care: Needs assistance with all aspects Mobility: Needs assistance with transfers; uses aids (manual wheelchair, standing frame) Communication: Non-verbal, has trialled switching	*Therapy* Physiotherapy, occupational therapy, speech therapy *Equipment* Purpose-built home Long and short leg callipers Easystander standing frame Manual wheelchair Postural insert Goanna potty chair Recently purchased *Discover* to access school curriculum
5A: Thi Buoi 15–24 years, mild/moderate disability	Female 15 years	*Diagnosis* Left hemiplegia, epilepsy, mild intellectual disability *History* Complex partial seizure disorder	Sores associated with AFOs Observed memory impairment and reduced language skills GOALS New stretching exercises Wear new AFOs consistently Regular contact with family about splints	Walks independently using AFO	Family active in Vietnamese community Attends mainstream high school Accesses modified curriculum	Lives with both parents 19 year old sister at home, two adult siblings out of home One parent working Parents' English limited Children are bilingual Sister attends appointments with her Lots of friends and family With CP agency for 14 years, but not regular service user Regular neurology appointments	Self-care: No help needed Mobility: Uses aids Communication: Some difficulties	*Equipment* Walker Articulated AFO—needs review

(continued)

Table A8.2 (continued): Summary of key factors in case stories, categorised according to the ICF framework

Case story	Personal factors	Health condition	Body functions and structures	Activities	Participation	Environmental factors	Support needs	Current Interventions
5B: Rosa 15–24 years, mild/moderate disability	Female 19 years	*Diagnosis* Spastic diplegia *History* Born at 33 weeks Intracranial haemorrhage	Surgery at age 13 for adductor tendon release	Swimming at least twice a week Uses a manual wheelchair for long distances Excellent language and cognitive skills GOALS Involve Rosa and family in helping her gain independence	Recently accepted into university Parents provide all transport Desire to transport herself to/from uni GOALS Assess university environment regarding modifications/aids needed Train in using public transport w/with wheelchair, other mobility options Apply for new equip including power wheelchair, insert	Received services from CP Australia as a child and adolescent Lives with parents, who provide care Active social life Lots of family and friends Older sister recently married Limited impact of services in EIP due to language barrier Parents run a delicatessen Mother recently stopped driving No carer support or respite services	Self-care: Needs some help with dressing, grooming, showering. Independent in toileting. Uses aids Mobility: Uses aids Communication No limitation	*Equipment* Walking frame Manual wheelchair (for long distances) Shower chair Handrails Toilet surround

(continued)

Table A8.2 (continued): Summary of key factors in case stories, categorised according to the ICF framework

Case story	Personal factors	Health condition	Body functions and structures	Activities	Participation	Environmental factors	Support needs	Current Interventions
6A:Peter 15–24 years, severe disability	Male 16 years	*Diagnosis* Dyskinetic cerebral palsy *History* unknown aetiology	Spasticity in all limbs	Uses a switch to operate computer Uses specialised software GOALS Maintenance of equipment for comfort, safety, independence	Year 11 in mainstream high school Full-time educational assistant School modified to enable access Potential to continue tertiary studies GOALS Investigate university and careers options	Receiving services from CP agency since diagnosis Two siblings aged 11 and 13 Younger brother resentful of Peter, affecting his school performance and behaviour Father runs own business, mother works part time Proactive parents GOALS Sibling camp for brother Info for parents on effect of disability on siblings Peter and brother to engage in leisure activities together	Self-care: Always needs help Mobility: Uses aids (powered wheelchair) Communication: Difficulty being understood by strangers; sometimes uses voice output device	*Therapy* Physiotherapy, occupational therapy, speech pathology, point percussion, acupuncture, naturopathy, hippotherapy *Equipment* Power wheelchair Laptop and specialised software Prone stander
6B: Anna 15–24 years, severe disability	Female 22 years	*Diagnosis* Spastic quadriplegia, intellectual disability, epilepsy. *History* Hit by a car at 5 years of age Two recent bouts of pneumonia from aspirating food	Flexion contractures of elbows, wrists, knees Bilateral hip dislocation Scoliosis Increased difficulty swallowing Consider PEG tube GOALS Mealtime management assessment Information about feeding through a PEG tube	Completely dependent on others for all her self-care needs Swallowing ability deteriorating Limited functional communication—indicates needs through facial expressions, vocalisations.		With CP agency since diagnosis Lives with mother; parents divorced; older brother lives out of the home Mother runs own business Little allied health service since leaving school. Has compensation Attended Education Support school Full-time carer during the day, mother cares for her at night	Self-care: Always needs help Mobility: Uses aids (manual wheelchair); always needs help with transfers Communication: Limited functional communication	*Equipment* Modified van Manual wheelchair Postural insert Symmetrikit chair Shower trolley Sling and hoist

(continued)

Table A8.2 (continued): Summary of key factors in case stories, categorised according to the ICF framework

Case story	Personal factors	Health condition	Body functions and structures	Activities	Participation	Environmental factors	Support needs	Current Interventions
7A: Usma 25–44 years, mild/moderate disability	Female 35 years	*Diagnosis* Mild spastic diplegia *History* Delayed walking (age 5) Late diagnosis at 16	Overweight Tenderness associated w/with AFOs GOALS Review AFOs Lose 5kg	Drives herself to work in modified car Uses an elbow crutch, AFOs	Works as receptionist	With CP agency for 29 years Migrated to Australia at 15 Married Parents live next door	Self-care: Uses aids Mobility: Uses aids Communication: No limitation	*Equipment* Elbow crutch Bathroom handrails Shower stool Fixed AFOs Drives modified car
7B: Tom 25–44 years, mild/moderate disability	Male 28 years	*Diagnosis* ABI resulting from car crash Right hemiplegia Mild cognitive impairment Frontal lobe damage Seizures *History* 3 years post-accident Takes seizure medication	Right hemiplegia mainly affects arm Aggressive outbursts, frustration at limitations GOALS Psych assessment and behavioural plan established	Behavioural difficulties, especially aggression Short attention span GOALS Hand function assessed especially regarding self-care skills and care program instigated	Difficulty finding work GOALS Identify supported workplace opportunities	Spent 9 months in rehab, 18 months in parents' home Siblings all married Parents and carers having difficulty with Tom's behaviour Received occupational therapy and social work briefly after moving home Regular neurology appointments Recently placed in a home with 4 men CP/ABI	Self-care: Needs help dressing, showering; sometimes needs help eating Mobility: Independent Communication: No limitation	

(continued)

Table A8.2 (continued): Summary of key factors in case stories, categorised according to the ICF framework

Case story	Personal factors	Health condition	Body functions and structures	Activities	Participation	Environmental factors	Support needs	Current Interventions
8A: Andrew 25–44 years, severe disability	Male 31 years	*Diagnosis* Spastic quadriplegia	Contractures in all limbs Scoliosis Bilateral hip dislocation Soft diet GOALS Ensure adequate nutrition to maintain body weight Safe and pain-free transfers Monitor equipment needs		Attends day program Swimming fortnightly Attends football matches with 'buddy' GOALS Increased opportunity for leisure activities	Lives in a group with four other adults with CP 24-hour care in the home Lived in the home for 3 years Moved frequently as a child Communication devices tried unsuccessfully Transported in taxis or van	Self-care: Always needs help Mobility: Uses aids (wheelchair); requires manual transfers Communication: Non-verbal ; expresses needs via facial expressions	*Equipment* Manual wheelchair Postural insert Shower commode Ceiling hoist and sling Hospital bed with rails Communication book Purpose-built home
8B: Lucy 25–44 years, severe disability	Female 35 years	*Diagnosis* Spastic quadriplegia Significant intellectual disability Epilepsy *History* Severe hypoxia at birth	Gastrostomy tube—nil by mouth Flexion contractures of elbows, wrist, knees Dislocated right hip Severe scoliosis Appears to be in pain GOALS Review manual handling, inserts and supports to limit pain	Fed via gastronomy tube Very limited functional communication, although appears to indicate when experiencing pain or pleasure through facial expressions	Concern re lack of stimulation GOALS Recreational 'buddy' to take Lucy on outings once a month	Lives in a nursing home for severely disabled people Cared for solely by mother until age 27 Parents divorced Mother visits regularly, advocates for Lucy Day program at nursing home 'Buddy program' ceased	Self-care: Needs help for all aspects Mobility: Not mobile; requires manual transfers. Communication: Limited functional communication.	*Therapy* Reviews Equipment Manual wheelchair Sunmate postural insert Shower trolley Bosun sling with head support

(continued)

Table A8.2 (continued): Summary of key factors in case stories, categorised according to the ICF framework

Case story	Personal factors	Health condition	Body functions and structures	Activities	Participation	Environmental factors	Support needs	Current Interventions
9A: Albert 45+ years, mild/moderate disability	Male 58 years	*Diagnosis* Spastic diplegia of unknown aetiology *History* Increased pain in upper body Using pain medication	Decreased mobility and strength over the last year Weight gain GOALS Reduce pain and medication use Increase strength and mobility	Independently mobile with aids. Independent in self-care activities Some difficulty using stairs on buses GOALS Maintain independence in mobility and self-care	Pool in retirement centre not heated—increase in spasticity GOALS Access community facilities to increase strength and reduce pain	Lives in retirement village w/ mother Has never worked Financially secure	Self-care: Uses aids (hand rails) Mobility: Uses aids (AFOs, Zimmer frame, electric scooter) Communication: No limitation	*Therapy* Physiotherapy and occupational therapy reviews *Equipment* Handrails in toilet and bathroom Scooter Zimmer frame AFOs
9B: Catherine (45+ years; mild/moderate disability)	Female 48 years	*Diagnosis* Spastic diplegia, epilepsy *History* Born at 32 weeks New medication for epilepsy	Increased seizure activity Right arm fracture from seizure—in plaster GOALS Maintain range of motion in shoulder Maintain lower limb strength and mobility	Cooks, cleans for her family Temporary loss of use of dominant hand due to fracture GOALS Assistance in self-care and meal preparation Regain full use of limb after plaster removal	Worked as a receptionist—now homemaker	Married w/ a 12 year old son Husband travels frequently Lives in purpose built home Extended family live away from city Physically demanding housework done by cleaner	Self-care: Uses aids (handrails) Mobility: Uses aids (trolley frame, limb callipers, electric wheelchair) Communication: No limitation	*Equipment* Lower limb callipers Trolley frame Handrails in toilet and bathroom

Table A8.3: Number of clients of CP agencies by age group, severity and geographical region

	Metropolitan areas[(a)]	Non-metropolitan areas
Mild/moderate disability		
0–4	304	73
5–14	1,363	503
15–24	687	209
25–44	723	142
45 and over[(b)]	1,016	191
Severe disability[(c)]		
0–4	313	113
5–14	1,125	437
15–24	760	240
25–44	946	167

(a) Includes clients of unknown location.

(b) Includes all clients aged 45 and over, regardless of disability severity.

(c) In the context of the archetypal cases analysis, severe disability was defined as always needing help in at least one core activity **and** needing help or using aids in at least two core activities.

Table A8.4: Distribution of age and disability severity among people with CP and like disabilities, 2003

	No.		Per cent		
Age group	Mild/moderate	Severe[(a)]	Mild/moderate	Severe	Total
0–4	600	2,300	19.5	80.5	100.0
5–14	4,500	4,400	50.7	49.3	100.0
15–24	5,000	5,700	46.8	53.2	100.0
25–44	4,300	5,700	42.6	57.4	100.0
45 and over	200	900	21.6	78.4	100.0
All ages	14,600	19,100	43.4	56.6	100.0

(a) In the context of the archetypal cases analysis, severe disability was defined as always needing help in at least one core activity and needing help or using aids in at least two core activities. All people with CP and like disabilities who did not meet these criteria were considered to have mild/moderate disability.

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

Table A9.1: Calculation of cost of meeting unmet need, using CSTDA and archetypal cases data

		Hours in ideal regime							Cost ($) of unmet need per client:		
Archetypal case categories		Clinician	Aide	Total	Clients in category	No. receiving 25–75% regime	No. receiving <25% regime	Cost of 75% regime ($)	receiving 25–75%	receiving <25%	Total cost of unmet need ($)
Metropolitan											
1	0–4, mild/moderate	792	47	839	304	114	137	43,138	14,379	28,758	5,573,378
2	0–4, severe	769	67	836	313	106	90	42,561	14,187	28,374	4,058,660
3	5–14, mild/moderate	282	4	286	1,363	665	307	14,932	4,977	9,955	6,363,384
4	5–14, severe	309	40	348	1,125	840	199	17,519	5,840	11,679	7,230,266
5	15–24, mild/moderate	94	8	102	687	275	267	5,189	1,730	3,459	1,397,445
6	15–24, severe	257	6	263	760	232	483	13,666	4,555	9,111	5,450,992
7	25–44, mild/moderate	170	14	184	723	136	560	9,380	3,127	6,253	3,928,804
8	25–44, severe	156	10	166	946	596	286	8,499	2,833	5,666	3,307,315
9	45 and older	144	8	152	1,016	459	548	7,808	2,603	5,205	4,047,017
					Total clients: 7,237						**Total cost (metro): $ 41,357,261**
Non-metropolitan											
1	0–4, mild/moderate	792	47	839	73	42	26	43,138	14,379	28,758	1,365,636
2	0–4, severe	769	67	836	113	66	27	42,561	14,187	28,374	1,705,737
3	5–14, mild/moderate	282	4	286	503	340	75	14,932	4,977	9,955	2,440,968
4	5–14, severe	309	40	348	437	277	137	17,519	5,840	11,679	3,212,849
5	15–24, mild/moderate	94	8	102	209	84	84	5,189	1,730	3,459	433,809
6	15–24, severe	257	6	263	240	80	160	13,666	4,555	9,111	1,822,524
7	25–44, mild/moderate	170	14	184	142	0	142	9,380	3,127	6,253	887,954
8	25–44, severe	156	10	166	167	50	104	8,499	2,833	5,666	733,322
9	45 and older	144	8	152	191	29	153	7,808	2,603	5,205	869,902
					Total clients: 2,075						**Total cost (non-metro): $13,472,702**

Note: Splitting by metropolitan vs. non-metropolitan has very little effect on the overall cost—using total client numbers per category and applying therapists' estimates of unmet needs averaged across metropolitan and non-metropolitan areas gives a total cost figure of $56,290,000

Table A9.2: Clients of CP agencies by state, 2003–04

State	No. clients	Per cent
NSW	1,336	14.2
Vic	4,272	45.5
Qld	1,514	16.1
WA	843	9.0
SA	1,433	15.2
All	**9,398**	**100.0**

Source: AIHW analysis of CSTDA NMDS data

Appendix B Technical appendix on the ABS 2003 Survey of Disability, Ageing and Carers

B.1 The survey

The 2003 Survey of Disability, Ageing and Carers (ABS 2004) was conducted throughout Australia during the period June to November 2003. The aims of the survey were to:

- measure the prevalence of disability in Australia
- measure the need for support of older people and those with a disability
- provide a demographic and socioeconomic profile of people with disabilities, older people and carers compared with the general population
- estimate the number of and provide information about people who provide care to older people and people with disabilities.

Information was collected from the three target populations:

- people with a disability
- older people (i.e. those aged 60 years and over)
- people who care for people with a disability and older people.

The survey covered people in both urban and rural areas in all states and territories, except for those living in remote and sparsely settled parts of Australia. It included people in both private and non-private dwellings, including those in cared accommodation establishments but excluding those in jails and correctional institutions.

Collection methods

Different data collection methods were used for the household component and the cared accommodation component of this survey.

Data for the household component were collected by trained interviewers, who conducted computer-assisted personal interviews. Where possible, a personal interview was conducted with people identified in any of the three target populations. Proxy interviews were conducted for children aged less than 15 years, for those aged 15–17 years whose parents did not permit them to be personally interviewed, and for those with a disability that prevented them from having a personal interview.

Cared accommodation includes hospitals, homes for the aged such as nursing homes and aged care hostels, cared components of retirement villages, and other 'homes' such as children's homes. The cared-accommodation component was enumerated in two stages using a mail-based methodology directed to administrators of selected establishments, who then selected survey participants using instructions provided by the ABS. A separate questionnaire was completed for each selected occupant meeting the coverage requirements.

The key measures used in the survey are described below.

B.2 Disability

For ABS survey purposes, a person has a disability if he/she has at least one of the following 17 limitations, restrictions or impairments, which has lasted, or is likely to last, for at least 6 months and restricts everyday activities (ABS 2004:72–3):

- loss of sight, not corrected by glasses or contact lenses
- loss of hearing, with difficulty communicating or use of aids
- speech difficulties (including speech loss)
- chronic or recurring pain or discomfort that restricts everyday activities
- shortness of breath or breathing difficulties that restrict everyday activities
- blackouts, fits, or loss of consciousness
- difficulty learning or understanding
- incomplete use of arms or fingers
- difficulty gripping or holding things
- incomplete use of feet or legs
- a nervous or emotional condition that restricts everyday activities
- restriction in physical activities or in doing physical work
- disfigurement or deformity
- head injury, stroke or any other brain damage with long-term effects that restrict everyday activities
- needing help or supervision because of a mental illness or condition
- receiving treatment or medication for any other long-term condition or ailment and still restricted in everyday activities
- any other long-term condition that restricts everyday activities.

The survey definition of disability aims to capture a broad range of people who have one or more impairments or limitations, or who have one or more health conditions which restrict everyday life. Thus, the 17 items were used as criteria to create the base 'disability' population which is the starting point for prevalence estimates.

Activity limitations and their severity

A 'specific limitation or restriction' is defined in the 2003 survey as a limitation in core activities (self-care, mobility and communication) or a restriction in schooling or employment. People who were identified as having a disability (using the above 17 criteria), and all people aged 60 years or over, were asked about their difficulty and need for assistance with various daily activities: self-care, mobility, communication, health care, housework, property maintenance, paperwork, meal preparation, transport, and cognition or emotion. Cognition or emotion refers to interacting, making or maintaining relationships, coping with feelings or emotions, making decisions or thinking through problems.

In the survey four levels of core activity limitation were determined, based on whether a person needs personal assistance with, has difficulty with, or uses aids or equipment for any of the core activities. A person's overall level of core activity limitation is determined by the highest level of limitation the person experienced in any of the core activity areas. The four levels of core activity limitation are:

- profound—unable to perform a core activity or always needing assistance
- severe—sometimes needs assistance to perform a core activity, or has difficulty understanding or being understood by family or friends, or can communicate more easily using sign language or other non-spoken forms of communication
- moderate—does not need assistance, but has difficulty performing a core activity
- mild—has no difficulty performing a core activity but uses aids or equipment because of disability; or cannot perform the activities of easily walking 200 metres, walking up and down stairs without a handrail, easily bending to pick up an object from the floor, and using public transport; or can use public transport but needs help or supervision; or needs no help or supervision but has difficulty using public transport.

Core activities comprise the following tasks contributing to the definition of profound or severe core activity limitation:

- self-care—bathing or showering, dressing, eating, using the toilet, and bladder or bowel control
- mobility —getting into or out of a bed or chair, moving around at home and going to or getting around a place away from home
- communication—understanding and being understood by others: strangers, family and friends.

Four sets of prevalence estimates of disability groups

In Australia, the five disability groups 'intellectual/learning disability'; 'psychiatric disability'; 'sensory/speech disability'; 'physical/diverse disability'; and 'acquired brain injury' provide a broad categorisation of disabilities based not only on underlying health conditions and impairments but also on activity limitations, participation restrictions and related environmental factors. These groups are generally recognised in the disability field and in legislative and administrative contexts in Australia (NCSDC 2004).

Four main approaches have been used to obtain estimates of disability (see Table 4.2). These provide a spectrum of estimates that may suit different purposes. All the estimates start with the base 'disability population', that is those defined by the survey as having a disability.

Estimates based on 'main disabling condition' relate to the condition that was identified by the survey respondents as causing the most problems, compared with any other conditions he or she may also have had. Using this method, the estimates of different disability groups are exhaustive and mutually exclusive. The numbers in each group total the number of people with a disability, as defined by the 2003 survey. People may, however, experience more than one disabling condition. The prevalence of a particular disability group will be underestimated if only main disabling conditions are considered. This approach to estimation is used when the focus is on people and each person is to be counted only once.

The remaining three sets of estimates are based on all disabling conditions and are in diminishing size, corresponding to an increasingly restrictive scope, according to severity, need for assistance or activity limitation:

- all disabling conditions
- all disabling conditions, plus activity limitations and participation restrictions
- all disabling conditions, plus severe or profound core activity limitations.

These estimates provide a better indication of the prevalence of particular disabilities. See AIHW 2003a:343 for more details.

B.3 Long-term health condition

In the survey, a long-term health condition is defined as a disease or disorder which has lasted or is likely to last for at least 6 months; or a disease, disorder or event (such as stroke, poisoning or accident) which results in an impairment or restriction which has lasted or is likely to last for at least 6 months (ABS 2004:76). In other words, people may have a long-term health condition, but not a disability, if the health condition does not result in an impairment or restriction which has lasted or is likely to last for at least 6 months. Long-term health conditions have been coded to a classification based on the World Health Organization's International Classification of Diseases and Related Health Problems (WHO 1992).

Appendix C Example case stories and therapy regimes

Two of the 18 case stories used in the archetypal cases exercise are presented below, together with the therapy regimes developed by one group of therapists. These serve to show how the interventions in the regimes relate to the details in the case stories and the goals specified, and how the regimes were modified in response to successive reductions in the amount of resources available.

Case story 2A: Typical 'average' severe case—Sarah

Sarah is 3 years 9 months of age and has spastic quadriplegia cerebral palsy, microcephaly, epilepsy and generalised developmental delay following Group B Streptococcal meningitis in the neonatal period. Sarah appears to have normal vision, with testing indicating she is likely to have moderate hearing loss, although due to the severity of her disability this has been difficult to accurately determine. She is the youngest of two children born to Anita and Tom, there being an older sibling, Grace, aged 10 years. The family live in the suburbs, Tom being a partner in an GP practice and Anita, while currently not working outside the home, previously trained as a high school teacher. Sarah has been registered with the city's main service agency that provides therapy to children with cerebral palsy for the last three years. During this time the family have been a regular user of the early intervention therapy services, receiving physiotherapy, occupational therapy and speech pathology services. The family supplement these services with private physiotherapy consultations on a regular basis.

Sarah has a range of equipment to assist her with function at home: a postural insert able to be mounted onto the stroller and high chair, a prone stander on loan from the Independent Living Centre (recent application made for funding to purchase a Jenx Monkey prone stander), fixed ankle foot orthoses and a bath seat. The family have settled into a regular routine in terms of Sarah's care, particularly around mealtimes as Sarah is particularly slow in managing to swallow soft-textured foods and liquid. Sarah is able to communicate by using her eyes to make simple choices and expresses her needs and feelings using vocalisations, facial expressions and body movements.

A recent meeting with the family resulted in the following goals being set for the next 6 months:

1. Sarah can hold her head up in the midline while sitting in insert for 15 seconds.
2. The family will be supported to investigate appropriate kindergarten options for Sarah for 2007.
3. Sarah will have a suitable wheelchair and insert for use at kindergarten and the community in 2007.
4. Sarah can tolerate wearing her AFOs in her standing frame for up to 15 mins on each occasion.
5. Sarah has various opportunities to experience switching in order to express her needs and develop her communication skills.

Table A8.5: Case story 2A—0–4 years old, severe disability (Sarah). Client-attributable time (including travel) associated with individual interventions in the ideal, 75%, 50% and 25% regimes

	Ideal regime		75% regime		50% regime		25% regime	
Description of intervention	**No. staff**	**Hours**	**No. staff**	**Hours**	**No. staff**	**Hours**	**No. staff**	**Hours**
Equipment recommendations and sourcing for kindergarten	2	6.0	2	6.0	2	6.0	1	1.0
Equipment sourcing for wheelchair	2	8.0	2	8.0	2	6.0	1	2.0
Funding applications for wheelchair, insert and communication device	2	2.0	2	2.0	2	2.0	2	2.0
Equipment clinics for wheelchair and insert	3	30.0	3	30.0	2	20.0	2	16.0
Communication review assessment for switching	2	10.0	2	10.0	2	10.0	2	6.0
Programming communication device to trial	2	32.0	2	32.0	2	32.0	1	16.0
Delivery and fitting of standing frame at home	1	2.5	1	2.5	1	2.5	1	1.0
Training use of and monitoring standing frame	1	6.0	1	6.0	1	4.5	1	4.5
Review fitting of foot splints	1	3.0	1	3.0	1	3.0	1	0.5
Family meeting to discuss kindergarten options	2	6.0	2	6.0	1	2.5	—	—
Team visits to kindergarten to assess access / staff support	2	48.0	2	32.0	1	12.0	1	4.0
Kindergarten visits for communication strategies	1	20.0	1	20.0	1	7.5	1	5.0
Kindergarten visits for physical activity participation	1	20.0	1	12.0	1	4.0	—	—
Kindergarten visits for play participation	1	16.0	1	12.0	1	6.0	—	—
Speech sessions for functional communication	1	48.0	1	24.0	1	10.0	1	6.0
Physio/occupational therapy intervention for head control	2	40.0	1	16.0	1	12.0	1	1.0
Parent education workshops e.g. Makaton	2	12.0	2	12.0	2	12.0	—	—
Mealtime management consult	1	5.0	1	5.0	1	5.0	1	2.0
Small group for hydrotherapy and technology	2	48.0	2	36.0	—	—	—	—
Small group for sibling	2	30.0	—	—	—	—	1	2.0
Review family meeting	3	9.0	3	9.0	2	7.0	1	2.5
Program/report writing	3	90.0	3	90.0	3	90.0	3	63.0
Total travel time		*111.0*		*73.0*		*36.0*		*9.0*
Total intervention hours (including travel)		**491.5**		**373.5**		**254.0**		**134.5**

Case Story 6A: typical ‘average’ severe case—Peter

Peter is 16 years old, the first of three children born to Allison and Mark. Peter has two younger siblings, Natalie (13 years) and Joshua (11 years). Peter was born with mixed cerebral palsy of the dyskinetic type with spasticity in all limbs, with aetiology unknown. The family have always resided in the city, with Mark having his own computer software business and Allison returning to work part-time as a beautician a few years ago. The family have been registered with the city’s association for children with cerebral palsy since Peter was 5 months old and have been regular and consistent users of therapy services. They are very proactive in the care and opportunities they provide for Peter, exposing him to a range of additional therapies such as point percussion, acupuncture, riding for the disabled and naturopathy over the years.

Peter has just entered Year 11 at the mainstream government high school he has been attending for the last four years. The school is highly supportive of Peter and over the years have made a number of infrastructure changes to accommodate Peter’s wheelchair and increase his access to the curriculum. He accesses the Year 11 curriculum and has a full-time educational assistant. Peter can independently operate his laptop computer using a switch and specialised software such as Discover, Co-Writer and Drag and Drop and a document holder. Peter concentrates well in class and is motivated to complete his work as independently as possible.

Peter is totally dependent on others for all aspects of self-care, including dressing, bathing, personal hygiene and mealtimes. He is continent in terms of indicating when he needs to use the toilet, however requires full assistance to do so. Peter uses a powered wheelchair with customised insert as his form of mobility, driving with a laterally placed T bar joystick. He is not a functional walker but stands regularly at home in his prone stander to assist with transfers. Peter communicates using verbal and non-verbal means, on occasions using a light writer voice output device as his speech can be unintelligible to strangers. His receptive language skills allow him to access age appropriate school curriculum and his family have never expressed any concerns in this area. Academically, it appears Peter has a bright future and his parents are keen to work with Peter to start pursuing and preparing for possible university options.

A few months ago, the family went on a day trip to visit some friends at their beach house on the south coast. The two families had such a lovely day together they were invited to spend the night and the rest of the weekend at the beach house, but unfortunately Allison and Mark had to refuse due to not being prepared with the range of additional supports they need to keep Peter comfortable. The incident resulted in an outburst of aggression from Peter’s younger brother Joshua, who desperately wanted to stay the night. Subsequently and on reflection, Mark and Allison have noted over the last year Joshua’s academic and behavioural performance at school has declined and he has mood swings that they were putting down to pre-puberty. However, it would seem Joshua is extremely resentful of his brother and all the attention and time he receives from his parents.

A recent meeting with the family and Peter resulted in the following goals being set for the next 6 months:

1. Joshua to attend a ‘sibling’ camp for children with brothers or sisters with disabilities.
2. Mark and Allison to be provided with support and information regarding the effects living with a child with a disability can have on siblings.

3. Peter and Joshua to independently engage in a leisure activity together at least once a month.
4. Peter and his parents to be provided with support and information regarding university placements and career options.
5. Peter to continue to be comfortable, safe and independent in his equipment allowing him to access the school and community environments.

Table A8.6: Case story 6A—15–24 years old, severe disability (Peter). Client-attributable time (including travel) associated with individual interventions in the ideal, 75%, 50% and 25% regimes

	Ideal regime		75% regime		50% regime		25% regime	
Description of intervention	**No. staff**	**Hours**	**No. staff**	**Hours**	**No. staff**	**Hours**	**No. staff**	**Hours**
Sibling camp for Joshua and Natalie	2	14.0	2	14.0	—	—	—	—
Sibling day camp for Joshua and Natalie	—	—	—	—	2	6.0	2	5.2
Sibling workshop for parents	1	5.0	1	5.0	1	5.0	—	—
Sibling information for parents	—	—	—	—	—	—	1	1.0
Investigation of appropriate shared leisure activity e.g. paintball	1	4.0	1	4.0	1	2.0	1	1.0
Individual psychology or social work sessions for Joshua	1	8.0	1	8.0	1	6.0	1	3.0
Individual psychology or social work sessions for Natalie	1	2.0	1	1.0	1	1.0	—	—
Investigation of leisure activities for Peter with his peers	1	2.5	1	2.5	—	—	—	—
Review of leisure activity	1	2.0	1	2.0	1	2.0	—	—
Liaison with leisure activity instructor or programme	1	6.0	1	6.0	1	4.0	—	—
Sourcing independent carer for Peter	1	3.0	1	3.0	—	—	—	—
Training Peter and carer in management skills	3	36.0	1	2.0	—	—	—	—
Tertiary / employment options workshop for parents and Peter	2	10.0	2	10.0	2	10.0	—	—
Linking family to community supports	1	3.0	1	3.0	1	2.0	—	—
School meeting to discuss post school options	3	9.0	2	6.0	2	6.0	—	—
Mealtime management review and training at home and school	1	6.0	1	5.0	1	4.0	1	1.0
Advocacy for family and Peter	2	8.0	2	8.0	1	2.0	—	—
Community access assessment i.e. Public transport	1	9.0	1	3.0	1	3.0	—	—
Equipment maintenance—postural insert	2	4.0	2	4.0	2	4.0	1	1.0
Equipment maintenance—technology	1	6.0	1	2.0	1	2.0	1	1.0
Equipment maintenance—self-care equipment	1	4.0	1	3.0	1	3.0	1	2.0
Equipment maintenance—standing frame	1	2.5	1	2.5	1	2.5	1	2.0
Equipment maintenance—power wheelchair and controls	1	4.0	1	4.0	1	4.0	1	4.0
Mini-team liaison	4	12.0	4	10.0	3	4.5	3	4.5
Family review meeting	3	7.5	2	5.0	2	5.0	1	1.0
Reports / programme writing	4	60.0	4	48.0	4	48.0	4	32.0
Total travel time		*44.0*		*22.0*		*17.0*		*6.0*
Total intervention hours (including travel)		**227.5**		**161.0**		**126.0**		**58.7**

Note: Total client-attributable time spent preparing and running sibling camp was divided by six (the average number of families per camp).

Appendix D Unit cost figures for the archetypal cases

There are very few studies of costs in the disability area. The material below draws from two well documented studies and detailed costing information from two service providers. It also compares salary rates from various service providers from three states of Australia, and unit price rates from a variety of service providers.

On the basis of this review of available data, two unit cost figures—one for clinicians and one for therapy aides—are arrived at for use in costing the archetypal cases.

Business rules for new Disability Professional Services

The Disability Services Commission of Western Australia conducted this study in 2003. It developed a set of business rules to provide clarity and consistency in funding of new Disability Professional Services (DSC 2003).

Data and costs were collected, from 11 participating service providers, on the activities that were directly and indirectly attributable to the client service and the other organisational costs involved in supporting the activity. It is important to note that the study was designed to develop a 'unit price' to be paid by the government agency and not the 'unit cost' of the service provider.

The study is somewhat flawed in relation to the unit price developed for the following reasons:

- Cost data were for a financial year (2001–02) and not at a particular point in time. This has the effect of limiting the cost impact of salary increases that were applied part way through the financial year. Later salary cost increases recognise the difference between rates applying between one year-end and the next. These are applied, but to a base that was artificially low in the first place.
- No allowance was included for depreciation of vehicles, equipment or buildings.
- Two of the three comprehensive service providers upon whose data the final price was determined do not pay rent for accommodation.
- The Program Support Cost element of the 'unit price' was adopted at 16% of salary costs rather than at the average 28% disclosed by the cost data. This was driven by the need to achieve ministerial approval of the rate.

Despite these, the data collected provide a sound evidentiary basis to support the non-salary component of service cost.

Funding of therapy for school age children

This comprehensive study was conducted in 1997 on behalf of the Cerebral Palsy Association of Western Australia, Rocky Bay Inc, and School Age Therapy Services with funding from the Disability Services Commission of Western Australia. The consultants were Maree Dyson Pty Ltd and the Yooralla Society of Victoria (Dyson and Moore 1997).

The project's purpose was to develop a funding formula to describe the cost of delivering therapy services to children of school age with disabilities. The findings and recommendations from the study were based on detailed data from the three sponsoring agencies and their staff.

The work done on setting an average of therapy 'time available for client service' and recommending a percentage to be considered as non-client service time provides a strong basis of evidence for use in development of a unit cost.

The study of costs made allowance for non-salary costs of 37%, comprising 7% for travel and 30% for general operating allowance. These percentages did not include an allowance for accommodation or depreciation.

Current unit costs for service providers

Home and Community Care—Victoria

The Victorian Health and Community Care (HACC) unit price for allied health in 2005–06 was $74.89 per hour (HACC unit prices 2005–06). A breakdown of cost components is provided—the amount includes allowances for 'amounts charged to building reserves or depreciation' (Aged, Community and Mental Health Divisions 1997). It also includes allowances for purchase of services, a cost component not applicable to CP Australia therapy services. After excluding purchase of services, the non-salary costs represent 53% of the cost of direct workers.

Cerebral Palsy Association of Western Australia

Unit cost data for 2005–06 available from CPAWA can provide a breakdown of cost components. No allowance is included for depreciation.

The 2005–06 unit cost was $64.65. The non-salary costs represent 30% of the cost of direct workers.

Salary rates

There is a high level of consistency between top of range in the Level 1 and Level 2 salary rates for service providers in Western Australia, Victoria and Queensland (Table A8.7). This indicates that a single national unit cost figure could reasonably be claimed to be representative of the cost of direct workers in all states.

Table A8.7: Top of range in the level 1 and level 2 salary rates for service providers

	Top of level 1	% difference to Average	Top of level 2	% difference to Average
CPAWA	52,418	101.2	61,169	100.7
Rocky Bay (WA)	50,598	97.7	60,475	99.5
Disability Services Commission (WA)	51,166	98.8	59,521	98.0
Therapy Focus (WA)	49,431	95.5	57,950	95.4
St John of God (Victoria)	53,247	102.8	62,202	102.4
Victoria public sector	53,080	102.5	62,751	103.3
Nova Health (Qld)	52,391	101.2	60,092	98.9
SA public sector	51,874	100.2	61,944	101.9
Average	*51,776*		*60,763*	

Sources: The Cerebral Palsy Association of Western Australia Ltd. Salaried Staff Enterprise Agreement 2004; Rocky Bay Incorporated Salaried Officers Enterprise Agreement 2002; The Western Australian Public Service General Agreement 2006; The Therapy Focus Enterprise Bargaining Agreement 2004; St John of God Health Care—Eastern Region and Health Services Union of Australia (health professionals) enterprise bargaining agreement 2005–2007; Health Services Union of Australia—health professionals—Victorian public sector—multiple business agreement 2004–2007; Nova Health Ltd Queensland Facilities Allied Health Certified Agreement 2004; South Australian Public Sector Salaried Employees Interim Award.

Non-salary costs

There appears to be some consistency in the rates of non-salary costs disclosed in the above costing studies. The percentage rates are as follows:

Disability Professional Services rate (WA)	28%
Funding of Therapy for School Age Children (WA)	37%
CPAWA	30%
HACC (Victoria)	53%

The Disability Professional Services rate includes travel as a salary cost. The only rate that includes any allowance for depreciation of buildings and equipment is the HACC unit price. This indicates that non-salary costs are likely to be in excess of 30% of direct workers costs.

For the HACC unit price, the higher percentage non-salary costs may be partly explained by lower direct workers' costs. Table A8.8 compares the HACC and CPAWA data in percentage and dollar terms. Direct workers' and associated costs are lower for HACC ($46.62) than for CPAWA ($49.69). This could reflect a different staff mix. It is known that the staffing of CPAWA services is clustered strongly at the top end of salary scales, with the majority of therapy staff having in excess of six years experience. The HACC mix may include a larger proportion of new graduates.

Table A8.8: Components of unit price—comparison of HACC and CPAWA data

	%		$		Adjusted $	
	HACC	CPAWA	HACC	CPAWA	HACC	CPAWA
Direct workers and associated costs (wages, superannuation, workers comp insurance, long service leave)	62.3	76.9	46.62	49.69	46.62	49.69
Travel (mileage and use of fleet vehicles)	3.3	0.9	2.49	0.59	2.49	0.59
Consumables (therapy consumables)	4.5	0.7	3.35	0.47	3.35	0.47
Purchase of services (purchase of direct services)	4.6		3.47	0.00	0.00	0.00
Assessment and coordination	2.0		1.49	0.00	1.49	0.00
Service management (manager salary)	8.5	4.8	6.34	3.09	6.34	3.09
Accommodation (rates, repairs and maintenance, non-capital furniture and equipment, insurance, cleaning, gas, water, electricity, depreciation, building reserves)	3.3	1.1	2.44	0.73	2.44	0.73
Other service costs (insurance, printing, stationery, computers, depreciation)	6.0	1.8	4.52	1.15	4.52	1.15
Organisational overheads (payroll, accounting, human resources, corporate management)	5.6	13.8	4.17	8.94	4.17	8.94
Unit price	$74.89	$64.65	$74.89	$64.65	$71.42	$64.65

Given that the 'purchase of services' cost in the HACC data set is not considered applicable in the context of the study, this has been removed in the final two columns of Table A8.8. Variations in 'assessment and coordination', 'service management' and 'organisational overheads' may be attributable to differences in reporting and structure. Taken as a group, HACC reports $12.00 and CPAWA $12.03 for these cost components. This leaves 'accommodation' and 'other service costs' as the major areas of difference (HACC $6.96, CPAWA $1.88). As both of these categories in the HACC data include depreciation and building reserve costs, it is reasonable to assume that the difference of $5.08 is related to this factor. If this factor was added to the CPAWA data it would result in a unit price of $69.73.

Comparison of available rates

Rates sourced from several service providers are compared in Table A8.9. The Disability Services Commission Business Rules rate is not included in the comparison as it is considered unrepresentative of costs of service providers, as explained earlier. The HACC unit price is included after adjustment to delete purchase of services costs. The CPAWA rate is adjusted for depreciation, by adding $5.08, based on the comparison of HACC and CPAWA accommodation and other service costs, above. This gives an average unit price/unit cost of $68.08.

It is not known whether the Scope and DHS rates include depreciation costs; if they do not, they should also be adjusted for depreciation. When this is done (again, by adding $5.08), the average unit price/unit cost becomes $70.62.

Table A8.9: Comparison of unit price/unit cost from four service providers

	HACC	CPAWA	SCOPE (Vic)	DHS (Vic)	Average
Salary costs	46.62	49.69			
Other operational and corporate costs	24.80	14.96			
Total	$71.42	$64.65	$68.00	$63.19	$66.81
Adjustment for depreciation allowance		+5.08			
Adjusted totals	*$71.42*	*$69.73*	*$68.00*	*$63.19*	*$68.08*
Adjust SCOPE and DHS for depreciation allowance			+5.08	+5.08	
Adjusted totals	*$71.42*	*$69.73*	*$73.08*	*$68.27*	*$70.62*

Unit cost for therapy aides

In order to arrive at a unit cost for therapy aides, a typical therapy aide salary rate was substituted into the CPAWA unit cost. The figure of $23.86 was used as the hourly salary cost for therapy aides—this was the annual rate for a therapy assistant under The Cerebral Palsy Association of Western Australia Ltd. Salaried Staff Enterprise Agreement 2004, plus superannuation, workers' compensation insurance leave loading and long service leave, divided by the hours available for direct or indirect service. Adding $14.96 for 'other operational and corporate costs' and $5.08 for depreciation (as for the unit cost figure for clinicians) gives a unit cost of $43.90 for therapy aides.

Summary

Regarding a unit cost for clinicians, the available costing studies provide support for a non-salary component of more than 30% of the direct salary cost base. The adjusted rates in Table A8.9 support the adoption of a unit cost of at least $68 per hour, and possibly $70 per hour. The comparison of various top of range salary rates across three states supports the application of a common rate nationally.

Regarding a unit cost for therapy aides, a figure of $44 per hour was arrived at by applying a typical therapy aide salary rate to the CPAWA unit cost formula.

Appendix E Archetypal cases professionals groups

Therapy and equipment regimes for the archetypal cases were developed by groups of allied health professionals from a range of disciplines in four Australian states. All of the professionals had experience working with people with CP and like disabilities. The groups included individuals with expertise in both children's and adult services, and regional and rural service delivery. The disciplines, and numbers of years' experience, of each of the members of these groups is listed below.

- New South Wales

– Physiotherapist	18 years
– Occupational therapist	13 years
– Speech pathologist	14 years
– Social worker	15 years
– Psychologist	16 years

- Queensland

– Physiotherapist	26 years
– Physiotherapist	12 years
– Occupational therapist	14 years
– Speech pathologist	19 years
– Social worker	20 years
– Psychiatrist	8 years
– Psychiatrist	12 years

- Western Australia

– Physiotherapist	20 years
– Physiotherapist	13 years
– Physiotherapist	8 years
– Physiotherapist	8 years
– Physiotherapist	2 years
– Occupational therapist	34 years
– Occupational therapist	30 years
– Occupational therapist	15 years
– Occupational therapist	12 years
– Occupational therapist	3 years
– Speech pathologist	16 years
– Speech pathologist	6 years

  - Speech pathologist 4 years
  - Social worker 10 years
- South Australia
  - Physiotherapist 28 years
  - Occupational therapist 24 years
  - Occupational therapist 3 years
  - Speech pathologist 28 years
  - Speech pathologist 13 years
  - Family support worker15 years

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List of tables

List of figures

List of boxes