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

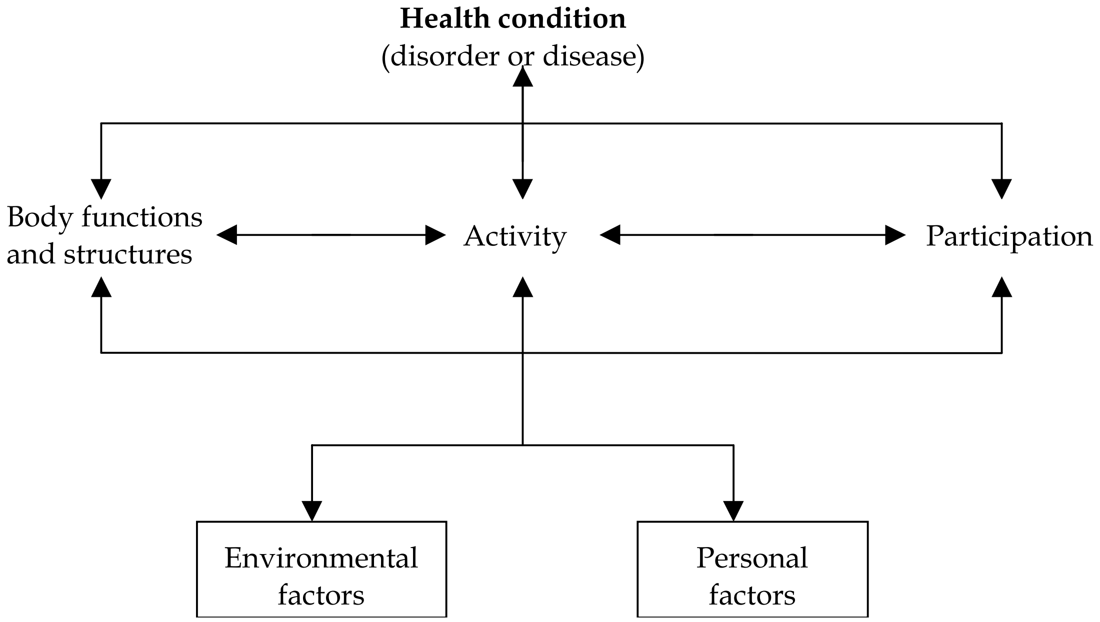
This study focuses on people with disabilities—disabilities related to, or similar to those related to, cerebral palsy. Functioning and disability concepts themselves shape ideas about the need for and outcomes from services and assistance. Recognising these connections, many CP Australia agencies use 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:

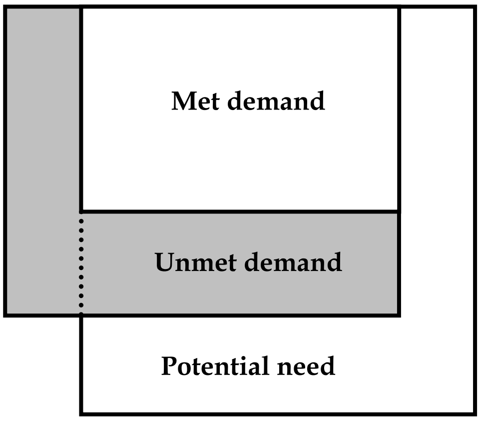
> any product, equipment or technical system used by a person with a disability, especially produced or generally available, preventing, compensating, monitoring, relieving or neutralising the impairment, activity limitation or participation restriction (ISO 2002).

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

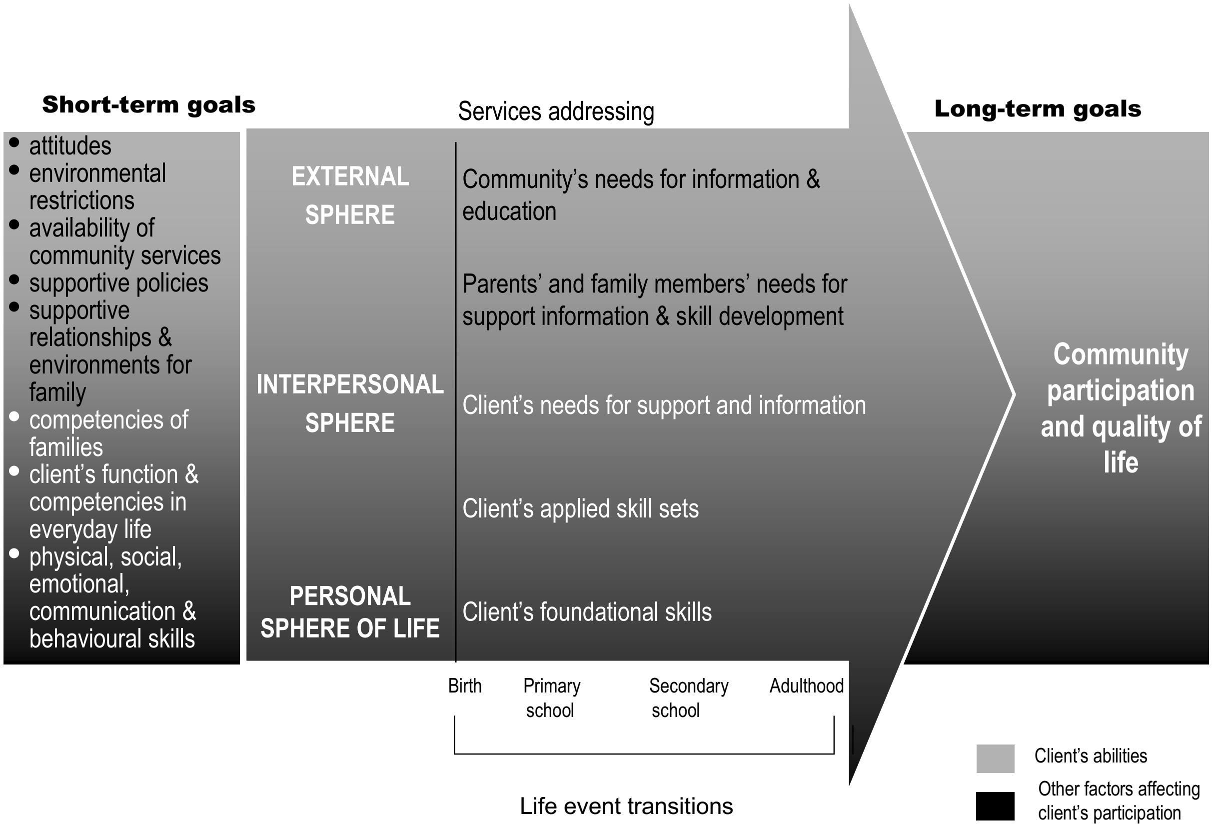
The way in which health care, including therapy, is provided to people with cerebral palsy has changed over time, paralleling changes in community attitudes about disability. There has been a shift away from focussing on trying to cure or normalise impairments, to considering the person's needs within 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.