

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

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

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Abbreviations

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

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

Symbols

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

Summary

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

Objectives

There were three key objectives:

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

Main information and data sources

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

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

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

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

People with CP and like disabilities in Australia

(Chapters 4, 6 and 7)

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

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

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

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

Therapy and equipment—do they make a difference?

(Chapters 3 and 5)

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

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

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

The nature of unmet need

(Chapters 5, 6, 7 and 8)

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

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

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

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

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

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

Based on combinations of these data sources, three estimates of the annual cost of meeting unmet need for therapy were generated. Each estimate can be interpreted as the additional

government funding needed by CSTDA agencies to provide therapy services for clients with CP and like disabilities.

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

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

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

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

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

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

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

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

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Project Advisory Committee

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