Submission to the Productivity Commission Inquiry: Disability Care and Support

The Economic and Social Impact of Cerebral Palsy

Executive Summary

People with cerebral palsy in Australia are marginalised and services to support them are underfunded.

We urge the Productivity Commission to consider the prevalence of this condition (1 in 400), its associated impairments, and its impact on the health and well-being of the individual and the family.

Cerebral palsy is complex and lifelong. In most cases the cause is unknown. There is no pre-birth test and there is no cure.

Prevention remains elusive as it is thought to be often the result of a complex causal pathway with interrelated predispositions and events.

Adequate and predictable funding is required to support people with cerebral palsy and their families to achieve an acceptable quality of life.

Key considerations in determining the costs associated with cerebral palsy include:

- The associated impairments, which contribute greatly to the overall disability and include intellectual impairments, and impairments of speech, vision, hearing and also epilepsy

- Intellectual impairment in particular, occurring for 45% of people with cerebral palsy, which severely affects communication, self-care, social and personal safety skills

- The unchanging incidence - by 2050 it is expected that there will be 47,600 people with cerebral palsy in Australia

- The Gross Motor Function Classification Scale, which is a useful measure in predicting costs, as the different levels of severity can be mapped to likely needs for medical interventions, therapy, equipment and supported care

- The financial cost estimate, which, in 2007, was $1.47 billion (0.14% of GDP). In per capita terms, the financial cost of cerebral palsy in Australia amounts to $43,431 per person with cerebral palsy per annum

- The need for a coordinated system of national surveillance of developmental progress, the development of secondary complications and emotional well-being which would facilitate timely and cost effective intervention

- The need for schools to be adequately resourced to allow children effective access to the curriculum. The costs associated with building modifications, equipment, teacher aide time and training for teachers and aides need to be considered

- The lack of timely access to therapy following medical interventions, which creates distress for families and diminished therapeutic and functional outcomes for children and adults

- The lack of access to age-appropriate long term accommodation which many family carers and young people with a disability express as their most significant concern

- The need for timely access to equipment that assists in mobility, communication, personal care and learning

- The adaptation and retention of jobs for people with cerebral palsy which can make a major contribution to reducing the financial and social burden for both the community and the individual

- The need for timely and flexible respite options that allow family members to take a break from their caring responsibilities

- The family carers' lack of availability for paid work which compounds the long term economic impact of the disability as they are unable to contribute to the taxation system and a superannuation fund

- The issues for family carers in rural and remote locations. Isolation often compounds the impact of the disability.

- In seeking to develop a scheme that fairly and adequately addresses the needs of people with a disability and their families, foundation principles may include:

  - Entitlement
  - Equity

- Informed choice
- Sustainability

Sources of Data

This report draws data primarily from the following sources:

- Access Economics (2008) *The Economic Impact of Cerebral Palsy in Australia in 2007,* Report for CP Australia*,* April 2008.
- ACPR Group, Report of the Australian Cerebral Palsy Register, Birth Years 1993-2003, December 2009.
- The practice experience of The Spastic Centre of NSW, which has 65 years' experience in planning and delivering services to people with cerebral palsy and their families.

Cerebral Palsy - Definition and Incidence

Cerebral palsy refers to a range of motor disorders arising from a non-progressive defect or damage to the developing brain in an infant. The condition is associated with prenatal factors, including certain viral infections and with a range of perinatal factors such as preterm birth. It is also occasionally associated with post neonatal factors such as head trauma.

In most cases the cause is unknown. For approximately 94% of people with cerebral palsy the brain injury occurs before one month of age. It is thought to be often the result of a complex causal pathway with interrelated predispositions and events. This makes prevention of the condition problematic.

For the foreseeable future, the incidence must be assumed to remain at one in 2-2.5 per 1,000 live births, making it the most common physical disability in childhood (Blair et al, 2001)**.**

With the current population, 600-700 infants with cerebral palsy are born in Australia each year.

The rate has remained relatively stable for the last 60 years. As survival rates for low birth weight and premature infants have increased, the number of children at risk of cerebral palsy has also increased.

Approximately 42% of people with cerebral palsy are born prematurely compared to 8% of the Australian population. There is no pre-birth test for the condition and there is no cure.

Cerebral palsy is a lifelong condition. Although non-progressive, the impact of the motor impairments increases with age and ageing occurs earlier. Motor disability in cerebral palsy ranges from minimal to profound.

Associated Conditions

Associated impairments contribute greatly to the overall disability. These include intellectual impairments (45%), and impairments of speech (60%), vision (37%), hearing (12%) and also epilepsy (31%). The likelihood and severity of associated impairments increases with the severity of the motor impairment and many will have a number of associated impairments. Their presence complicates support and intervention and increases costs of care.

Intellectual impairment, usually accepted as an IQ below 70, can severely affect communication, self-care, as well as social and personal safety skills.

The primary motor disability may also lead to secondary impairments that involve the skeletal system. Hip displacement occurs in up to 90% of people with severe spasticity. Contractures, scoliosis and significant pain are also common.

Almost 25% of children and adolescents with cerebral palsy have urinary incontinence (Access Economics, p.11).

Prevalence

In 2007, 33,797 Australians were estimated to have cerebral palsy. The number of Australians with cerebral palsy is projected to increase with population and to remain at 0.2% of the total.

In the absence of preventative or curative strategies being discovered, the number of people with cerebral palsy will increase as the population increases and the life expectancies of those living with cerebral palsy increases.

By 2050 it is expected that there will be 47,600 people with cerebral palsy in Australia.

Improvements in medical care and social support have meant that most people with cerebral palsy now live into older age. Those in their fifties to seventies are the first of this group to be followed. Survival outlook is good, although lower than the general population. The risk of mortality before the age of 30 years is significantly higher for those with severe intellectual or motor impairment and for those who have severe multiple impairments.

Range of Severity

Cerebral palsy usually has a substantial effect on both the function and the health-related aspects of quality of life for the individual and their family. The impact of the condition differs widely and depends on the type of cerebral palsy and its severity.

Classification of cerebral palsy is complex and has been subject to debate. The traditional classification is based on the type and bodily distribution of motor impairment, with a description of associated impairments.

Eighty percent (80%) of people with cerebral palsy will have spasticity as the predominant feature (Australian Cerebral Palsy Register, 2006). Spasticity may occur on one side of the body only (right or left hemiplegia) and usually the upper limb is more affected making fine motor tasks and activities of daily living difficult. Spasticity may also affect the lower limbs only (diplegia) or all four limbs (quadriplegia).

Dyskinesia occurs in 10-12% of people with cerebral palsy and may involve rigid posturing or abnormally slow, writhing movements.

A small percentage (6-9%) experience ataxic cerebral palsy which is characterised by problems with balance and depth perception.

In considering the severity of cerebral palsy across the different diagnostic categories, function and mobility are usually given primary consideration.

Approximately 50% of people with cerebral palsy are able to walk independently, 25% require an assistive device for mobility and 25% are unable to walk (Korman et al, 2004).

Another measure widely used in the classification of cerebral palsy is the Gross Motor Function Classification Scale. This is a I-V scale, with one representing the least severe forms of cerebral palsy and five representing the most severe forms. The scale is useful as a shared communication tool between practitioners.

The Gross Motor Function Classification Scale is also useful in predicting costs, as the different levels of severity can be mapped to likely needs for medical interventions, therapy, equipment and supported care.

The Cost of Cerebral Palsy in Australia

The cost of care for people with cerebral palsy is high, particularly for those with multiple associated disabilities.

In 2007, the financial cost of cerebral palsy was $1.47 billion (0.14% of GDP). Of this:

- 1.03 billion (60.9%) was productivity lost due to lower employment, absenteeism and premature death of Australians with cerebral palsy
- 141 million (9.6%) was cost to the community including welfare payments and taxation foregone
- 131 million (9.0%) was other indirect costs such as direct program services, aids and home modifications
- 129 million (8.8%) was the value of informal care
- 40 million (2.8%) was direct health system expenditure

Of the health system expenditure, 48% was expended though hospitalization. Allied health costs accounted for a further 16.5%. The remainder was made up of the costs of medication, pathology, imaging, GP visits and specialist consultations (Access Economic Report, p.30).

For the individual and their family, health costs often represent a significant burden. As an example of the impact of health costs, significant hardship can be experienced by family carers who need to access the services of a GP for their adult son or daughter. Complexities of transportation, in combination with issues of physical access in consulting rooms mean that home visits are often the only practical option. Significant costs are often borne by the individual for this service.

In per capita terms, the financial cost of cerebral palsy in Australia amounts to $43,431 per person with cerebral palsy per annum.

When the value of lost well-being is included, the cost of cerebral palsy is over $115,000 per person per annum. Of this, 37% is borne by the individual and /or their family (Access Economics, p vii.).

As a lifelong condition with early onset, significant incidence and no cure, cerebral palsy is a substantial cost to the community. Strategies that contribute to amelioration of the financial and social cost of cerebral palsy are recommended, while research into the causes and prevention strategies continue.

Surveillance and Intervening Early

Timeliness in intervention for children, young people and adults, using evidence based practices, will increase function and participation and reduce secondary disablement through deformity.

For young children, in general, the earlier treatment and social support is offered, the better the chance of reducing the impact of the developmental disability.

Diagnosis can take many months and sometimes years and support for families during the diagnostic period assists with emotional outcomes for the family.

For older children, teenagers and young adults, interventions are usually most effectively geared to changes in physical status or life transitions. For example, entering school, leaving school and seeking employment are key times for intensive intervention, as are physical growth spurts. Many people with severe cerebral palsy benefit from on-going coordinated care and support services.

A coordinated system of national surveillance of: developmental progress, the early identification of trends towards secondary complications, and issues of mental health would facilitate timely and cost effective intervention.

In Sweden such a system has been highly effective in reducing costs and the need for surgery in children with cerebral palsy.

Health and Social Support Service Delivery

Such a surveillance system would also facilitate the timely access to appropriate medications, including pain management, muscle relaxation and seizure control and orthopedic surgery where necessary. Access to allied health services and psychological support would also be more targeted and timely though the use of a surveillance system.

A team of health care professionals is required for the coordinated management of cerebral palsy and to address the specific concerns and life goals for the individual and their family.

Typically, interventions may be required in the areas of physical therapy, occupational therapy, speech pathology, education, therapeutic recreation, counseling, emotional and behavioural support, drug therapy, surgery, orthotic devices, mobility equipment, equipment to assist with daily living and environmental modification, and communication aids. It also includes systems that support communication - ranging from low technology such as picture boards to high technology systems such as speech generating devices.

Interventions are generally goal directed and aim to optimise physical and social functioning. There is a focus on developing independence, self-esteem and emotional well-being.

Services are usually provided through government and non-government providers from the health and disability service sectors. Some families and individuals also access private providers.

In NSW, commonly the delay in accessing services is unacceptably long due to scarce resources. This is particularly so in some rural locations.

In recent years, drug treatments for pain management, muscle relaxation and seizure control have played an increasingly important part in the management of cerebral palsy. For muscle management in particular, a period of therapy following the medical intervention is critical to maximise outcomes.

Medical interventions are provided through the hospital system and follow up therapy is not routinely provided through the same service channel.

Lack of timely access to therapy following medical interventions creates distress for families and wasted opportunities for children.

The model used in Victoria, where funding is attached to the intervention so that families can purchase post intervention services, is regarded as resource effective.

Access to Education

For children and young people, access to education often presents an array of difficulties. Whilst, under legislation, schools are required to accept children with complex disabilities such as cerebral palsy, often the school is not adequately resourced to offer effective access to the curriculum.

Costs associated with building modifications, equipment, teacher aide time and training for teachers and aides are significant. In particular, the cost of teacher aide time in non government schools often presents barriers to meaningful inclusion.

Appropriate Respite and Accommodation

There is a serious shortage of age-appropriate day care and long term housing for adults with cerebral palsy. A significant number of family carers are still caring for their sons and daughters in their fifties at home.

Many family carers and young people with a disability express the lack of access to age-appropriate, long-term accommodation as their most significant concern.

To support family carers, timely access to respite, residential and non-residential, is critical.

Adults with cerebral palsy are still inappropriately accommodated in nursing homes, both for long term and for respite care. There is a severe shortage of age-appropriate day care and longer term housing for younger people with cerebral palsy.

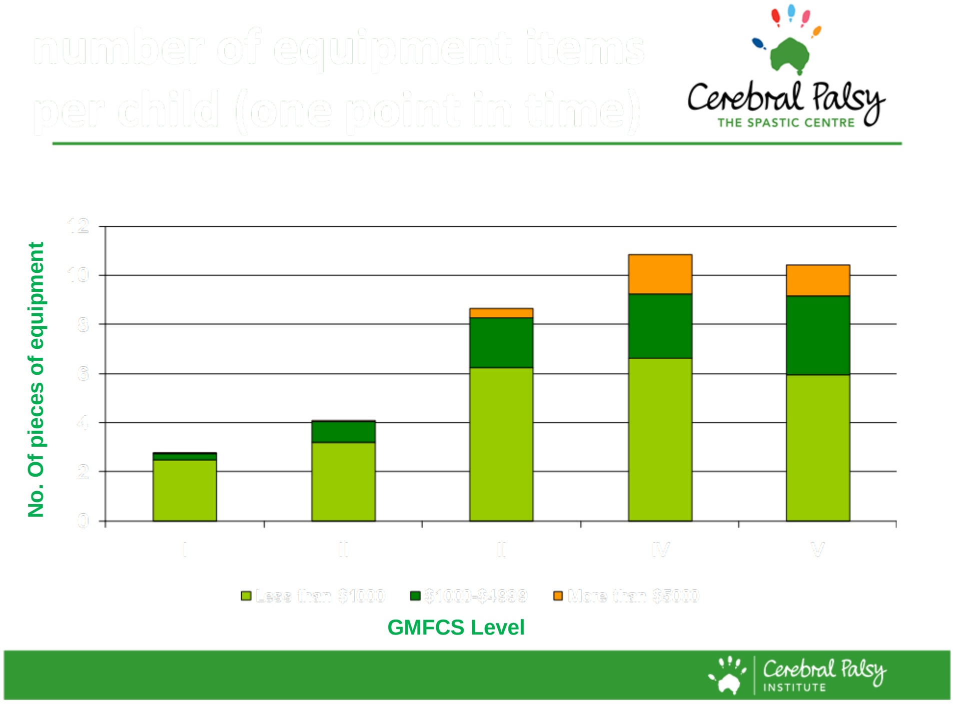
Transport, Equipment and Home Modifications

The burden is, care is increased significantly by the lack of timely access to equipment that assists in mobility, communication and personal care.

The situation is compounded by the fact that children outgrow their equipment. Certainty and timely funding is needed.

Overall, the costs for aids and equipment for people with cerebral palsy was estimated at around $6.4 million in 2007(Access Economics Report, p.39).

It should be noted that the higher the level of the person's disability, the more costly the equipment required. Typically a person with cerebral palsy will require multiple pieces of equipment at any one time which will need to be renewed every 3-5 years due to growth issues for children and or changes in functioning for adults.



Participation in employment, recreation and the life of the community involves significant additional costs in transport, equipment and personal care. Continence aids are expensive and not fully funded.

Many adults with cerebral palsy rely on taxi transport. Although this attracts a 50% subsidy, it is still significantly more expensive than public transport.

For the child or adult with a significant physical disability, the cost of modifications to a family vehicle so that it can safely accommodate a wheelchair is high. The cost of the vehicle modification to accommodate a powered chair is between $20,000 and $50,000, depending on the model of vehicle. Currently there is no reliable funding source for this need. Families sometimes seek the support of community groups for assistance.

For people with cerebral palsy who wish to pursue driver assessment and training programs, the costs are high and additional to the cost of vehicle modifications.

For many families, if they have rented or purchased the family home prior to the birth of a child with cerebral palsy, relocation may be required as not all homes can be satisfactorily modified. For many this involves great expense. The average cost of a home modification is $7,995 (Access Economics, p.39).

Employment and Community Inclusion

Adaptation and retention of jobs for people with cerebral palsy can make a major contribution to reducing financial and social burden for both the community and the individual.

Adults with cerebral palsy who have high support needs have well under half the workforce participation rate of the general population (Australian CP Register, McIntyre, S. 2006).

Enhanced employer incentive schemes, job tailoring and transport assistance are required.

One model that has been successfully trialed with young adults with cerebral palsy has involved supporting the development business ventures through small grants ($4000-$5000). Expert advice with the development of business plans has been included as part of the package. The businesses involved home-based freelance video and editing, hand-made greeting cards with original artwork and the development of a database on accessible travel. All businesses have been successfully launched.

There is a significant employment gap for those who are unable to secure open employment but whose intellectual capacity warrants an alternative to a traditional supported employment option. A small grants program may assist in addressing this issue.

In contrast, a significant number of people with cerebral palsy need non-vocational options so as to engage in activities that are meaningful and enable them to participate in and contribute to the life of the community. A range of service models that incorporate group based and individualised approaches are required to achieve genuine community inclusion.

There is also a need to invest in community development strategies to support communities to be more welcoming and inclusive of people with cerebral palsy. This will serve to facilitate social and economic contribution.

Carer Issues

A large proportion of people with cerebral palsy are profoundly disabled and rely on the informal care provided by parents and other family carers.

To assist family carers, programs that target social and emotional support are of particular importance. For family carers, the uncertainly of the availability of services, support and funding contributes to an erosion in well-being.

Of particular significance for family carers are the limitations that the disability of their son or daughter places on their capacity to work in paid employment.

The physical and emotional impact of caring, for many, diminishes physical and emotional well-being. Family carers may also be at increased risk of mental health problems. This, coupled with practical challenges in obtaining sufficient and appropriate care, prevents many family carers from entering the workforce.

Family carers accompany their family member with cerebral palsy to medical and allied health appointments, assist with mealtimes and personal care during hospitalistation, and care for them at home.

Many after school programs are unable or unwilling to take a child with cerebral palsy because of the complexity of their care needs. Often they lack the physical facilities, specialised equipment and staff necessary to care for the child. Similar issues commonly arise in school holiday programs.

Family carers are also often involved in transporting their child to school. This is particularly the case in rural and remote areas where there are no accessible taxis available and school buses are not equipped to accommodate the child with a complex physical disability. Similarly, on school excursions, parents often drive behind the school bus and accompany the child on the outing, limiting both their own capacity to engage in other activities such as work, and also restricting the peer interaction available for their child.

Where parents have been able to engage in paid employment during their child's school years, the absence of full time post school programs for their son or daughter often means that parents, particularly mothers, are forced to cease or to significantly reduce their engagement in the workforce.

The family carers' lack of availability for paid work compounds the long term economic impact of the disability as they are unable to contribute to the taxation system and to a superannuation fund.

Many families report that the uncertainly of the availability of funding and services has a serious negative impact on their well-being. Commonly, lack of respite services and long term accommodation options for adult sons and daughters is highlighted.

Rural issues

The issues for family carers are often compounded in rural and remote locations.

An example is the need for families in remote locations to travel to a regional centre to trial mobility or communication equipment offered by commercial suppliers. With uncertainly and extensive delays in funding being made available for this equipment, commercial suppliers are reluctant to bear the cost to travel to regional centres and families consequently face lengthy delays and additional costs in travel.

Independent accommodation options for adult children, where they are available, sometimes mean that families are split when accommodation is not available in the local area.

Indigenous Australians and those from culturally and linguistically diverse backgrounds face additional disadvantage.

Principles of a Funding Scheme

We endorse the principles for a national funding scheme, as outlined by the National Disability Service. Specifically, these are:

- Entitlement
- Equity
- Informed choice
- Sustainability

For people with cerebral palsy, there is a need for a scheme that is tailored to individual need and delivers adequate resourcing with certainty.

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