

**SUBMISSION TO THE STANDING COMMITTEE ON
FAMILY AND HUMAN SERVICES
INQUIRY INTO BETTER SUPPORT FOR CARERS**

[Preparation of the submission was greatly enhanced by input from a group of parents of both young children and adult children with Cerebral Palsy and we thank them for their assistance]

One Parent's Story

My triplets (now aged 10 years) were 12 months old when one of them, S, was diagnosed with Severe Dyskinetic Athetoid Cerebral Palsy. A Physio suggested I call The Centre for Cerebral Palsy. They arranged someone to come home. We would attend 'Early Intervention' and have on site Physio, Speech, and Occupational Therapists that would help S to acquire the things she needed. Necessary equipment like a fully supported custom made insert for her wheelchair, a standing frame, communication devices and compits.

S was constantly in hospital with chronic asthma and lung disease; she would get the flu and sometimes end up in ICU. She would aspirate her food and drink, which would result in a bacterial lung infection. Her weight dropped due to illness and her movements. We were faced with her having a Gastrostomy operation so that she would get all her nutrition, calories and medication through a tube inserted into her stomach.

Sleep deprivation was still an issue and I rarely slept in my bed. I would sleep with S.

When the triplets were seven my husband and I separated.

With S growing stronger and heavier, lifting, dressing and assisting her was becoming more difficult for me. I developed Carpel Tunnel Syndrome in both my wrists and my back felt like it was breaking.

I still need to get up twice through the night to reposition S as her hips are causing pain. She is scheduled to have hip surgery in a few months and I'm not looking forward to the procedure or the rehabilitation. The therapists from The Centre for Cerebral Palsy will support and assist me after the surgery which is reassuring for me.

The Centre for Cerebral Palsy provides me with out-of-home respite Friday to Sunday and this is so important because I can attend the sporting activities that my other two children play.

Thanks to The Centre for Cerebral Palsy for providing me with their services and resources over the last 10 years and making me and my family's life a little easier.

SCOPE OF THIS SUBMISSION

This submission is structured as follows:

- About The Centre for Cerebral Palsy
- Facts about Cerebral Palsy (CP)
- Response to the Inquiry's Terms of Reference
 - the role and contribution of carers in society and how this should be recognised
 - the barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment
 - the practical measures required to better support carers, including key priorities for action
 - strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future.

ABOUT THE CENTRE FOR CEREBRAL PALSY

The Centre for Cerebral Palsy has a long history of service in the Western Australian community. The Centre is a non government, not for profit disability service provider, providing services and support to more than 1000 children and adults living with cerebral palsy and their families throughout WA.

We provide a range of services to address the unique needs of the people with whom we work. These services include accommodation support, physiotherapy, speech pathology, occupational therapy, social work, psychology, early education, respite, health promotion, employment, alternatives to employment, and recreation. Therapy, accommodation and employment services and day activities are provided across a number of geographic locations.

Specialised technology and equipment is developed to improve the capacity of a person living with cerebral palsy to carry out daily activities and participate in their local community.

The Centre is pleased to have the opportunity to make a submission to this inquiry. Our submission will focus on the needs of carers of children and adults of Cerebral Palsy (CP).

FACTS ABOUT CEREBRAL PALSY (CP)

CP is a permanent physical condition that affects movement. Except in its mildest forms it can be seen in the first 12-18 months of life, when children fail to reach movement milestones. Australians under 18 are three times more likely to be diagnosed with CP than cancer. There is no pre-birth test, no known cure and severity is on the increase, partly due to improved medical interventions throughout pregnancy and at birth. Also due to medical interventions and technology, people with CP are now living until older ages.

For most people, the cause of CP is unknown. Babies most at risk are those born prematurely or with low birth weight. CP is also associated with many perinatal factors (such as maternal iodine deficiency, rubella or cytomegalovirus infection), birth asphyxia, multiple pregnancy and, occasionally, with postneonatal factors such as head trauma or cerebral infections.

CP can vary in severity, from a weakness in one hand to an almost complete lack of movement. Sometimes the movements of people with CP can be unpredictable, muscles can be stiff or tight, and in some cases people may have shaky movements or tremors, and there are increased risks of intellectual, speech, vision and hearing disabilities, and epilepsy. About a quarter of people with CP are permanently restricted to a wheelchair and unable to eat or speak independently, requiring 24 hour care.

There are different types of cerebral palsy:

- Spastic cerebral palsy - this is the most common form and occurs where the muscles are tight and stiff making movement difficult.
- Athetoid cerebral palsy - people with athetoid cerebral palsy often have very weak muscles and feel floppy when carried. Involves unpredictable movements.
- Ataxic cerebral palsy - this is the least common form and involves shaky, unsteady movements and can also cause problems with balance.
- Mixed types - many people do not have just one type but a mixture of several of the above types of cerebral palsy.

RESPONSE TO THE INQUIRY'S TERMS OF REFERENCE

The role and contribution of carers in society and how this should be recognised

A large proportion of people with CP have profound disabilities and live at home with informal, free-of-charge care provided by parents and/or other family members. Being a family carer is a 24 hours/7days a week role and family carers wear many occupational hats - all unpaid. From The Centre's perspective, our work with children and adults with CP is greatly enhanced by our partnership with parent and family carers.

Unpaid caring brings emotional benefits both to the carer/s and the family member for whom they are caring. Unpaid family carers do not choose to care: generally, for families of children with disabilities, unpaid caring is just another one of their family responsibilities, which brings them great satisfaction as well as enabling their child or family member to live a normal life within their own community. However, unlike other parenting, parenting a child with severe disabilities is a life-time role and never-ending commitment and a parent's responsibilities do not end when their child reaches adulthood.

Parents and other family members who care for children and adults with disabilities save the community a considerable amount of money through their unpaid caring role.

It has been estimated that in 2003 there were approximately 247,000 unpaid (family) carers in Western Australia alone, with 39,000 being primary carers (someone who provides most of the ongoing assistance for at least one core activity - communication, mobility or self-care).¹

While these hours of informal care are provided free-of-charge, they are not *free*. Time spent caring is time that cannot be directed to other activities such as paid work, unpaid work (eg housework, caring for other family members) or leisure.

While caring for a family member with disabilities does bring great satisfaction to carers, it also brings huge challenges. Caring for someone who has a disability can be an enormous task, as evidenced by "One Parent's Story", summarised at the beginning of this submission. The Committee will be aware of the research regarding the adverse social, physical and emotional impacts on carers, so we do

¹ Statistical Overview of Carers in Australia and Western Australian, WA Department for Communities, www.community.wa.gov.au/Communities/Carers/Carers_Statistics

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not intend to repeat these findings here. However, we are aware through our own work with people with CP and their families that much greater attention must be paid to the health and wellbeing needs of family carers and to the siblings of children and adults with disabilities, as well as to the financial impacts on these families.

There is need for greater recognition of the value of the unpaid caring role; and of the challenges that caring brings. Initiatives are needed that raise the profile and status of unpaid caring and increase the importance that society places on it.

Greater recognition is also needed for the work of paid carers.

However, recognition of the value of the role of carers of children and adults with disabilities will not be achieved without the following:

- increased knowledge and understanding by the general community about disabilities and how to provide services appropriately
- increased opportunities for people with disabilities to become involved in meaningful activities
- increased acceptance of diversity by the general community and an increased belief in a fair go for everyone
- increased integration of people with disabilities into the wider community.

Governments must provide better support to people with disabilities and help to shape positive attitudes towards them and their carers.

The barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment

The most self evident barriers to social and economic participation for carers are:

- the time constraints imposed by caring and the exhaustion many carers of children with disabilities experience
- the financial burdens on family carers
- the physical burdens on parent carers, especially as their children grow older and become heavier, and the high costs of equipment which can ease this physical burden
- poor community perception of people with disabilities, and poor access for wheelchairs, etc
- the lack of recognition of the contribution family carers make to our community
- lack of respite/alternative care options
- lack of information, or knowledge about where to get the information, about supports and services.

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For example, in relation to employment, family carers usually have no choice but to take time off work to accompany people with CP to medical appointments, stay with them in hospital, or care for them at home, sometimes at very short notice. Carers may also take time off work to undertake many of the unpaid tasks that the person with CP would do if they did not have CP. Even flexible workplaces often find it hard to accommodate these absences.

As a result, there is a strong link between reduced workforce participation and unpaid care. Carers of people with a disability are less likely to participate in the paid workforce, or be paid salaries reflecting their skills and qualifications. Parents of young children using The Centre for Cerebral Palsy's services report that this leads to breaks in their careers which not only disadvantage their families financially but also rob them of the satisfaction they would otherwise have gained from professional achievement. Governments need to fund appropriate levels of care and respite services for carers of children and adults with CP.

The practical measures required to better support carers, including key priorities for action

As the Committee is aware, carers differ in their needs and issues, and a 'one size fits all' approach cannot meet their needs. There is a need for greater flexibility within the disability sector, particularly in relation to funding. Increased funding will be needed, to reflect the financial contribution family carers make to the Australian economy through their unpaid care. Some practical measures which are needed or should be expanded are summarised below:

1. Parents at a recent focus group organised by The Centre agreed that regular opportunities for overnight and weekend respite provided essential support not only for themselves but also their other children, who can often find coping with their brother or sister's disability a challenge. Increased funding and placements for adequate and free or heavily subsidised overnight and weekend respite was seen as one measure which alone would significantly enhance support for carers. This would not only lead to improved care for people with disabilities, but also ease the stress on their families, who would be relieved of the added anxieties they experience when their family members are in respite or day activities.
2. People with CP frequently require expensive equipment to increase independence and quality of life, such as wheelchairs, walkers and splints, ramps, showering and bathing aids and these are financed largely by people with CP and their families and carers. Children outgrow this equipment (sometimes, due to long waiting lists, by

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the time the equipment is delivered), adding to carers' expenses. Further financial assistance from Government is necessary to provide reimbursement for large items in a timely manner. This financial assistance is more than compensated by the financial contribution carers make to the community.

3. Obviously Government leadership with business to ensure much greater workplace flexibility and options would most assist carers to balance their work and caring responsibilities.
4. The needs and feelings of siblings of people with disabilities are often overlooked within their families and by support agencies, resulting in feelings of isolation and emotional distress. Siblings can and often do play a key role in the emotional and social health of a person with special needs, and increased awareness around sibling issues, and services for families, are essential. If siblings are supported, it is likely the whole family will function more positively.
5. The challenges and stresses of caring contribute to increased family and marriage breakdown. Greater funding is required for non government funded disability support services to enable them to provide social workers, psychologists and counsellors to provide emotional support services to the families of their clients.
6. The eligibility criteria for benefits and payments needs to be changed, based on accurate calculations of both the real financial liability carers face and the unpaid contribution they make to Australian society - differentiating between costs of caring for children and adults, between costs of caring for children of low needs and high needs, etc.
7. A flexible funding system such as a 'voucher' funding system would enable carers to spend Government assistance as they choose, according to their varying needs, including their own health and wellbeing needs.
8. Increased funding and support to non government disability service providers is needed to enable them to facilitate support groups for unpaid carers.
9. information is a vital need, especially for new parents. An information data-base is needed for carers on services, programs, supports available -
10. The waiting times for vital equipment must be shortened.

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Strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future.

A critical issue facing all disability service providers across Australia, including The Centre for Cerebral Palsy, is the recruitment and retention of paid carers. Increased funding to enable further pay rises for carers would have a positive effect on staff retention rates and lead to enhanced services for clients (and therefore, parents and family members). A stable, professional and well-trained workforce is essential if organisations such as ours are to provide the varied range of activities and services parents' desire for their children who have disabilities. This would assist to alleviate the anxieties family carers, especially aging parents with adult children, feel when planning for the future, including their own deaths.

Other strategies which would assist include:

- more technology-based medical interventions to change disability outcomes, not merely sustaining current functional levels
- increased technology, and greater investment in robotics, to give greater independence to people with disabilities and thereby reduce physical and time burdens on carers
- planning of group homes with housing available for parents nearby - ie 'cluster' housing. Parents would be able to continue connections with adult children as they age, and also be able to support paid carers.

Above all, a greater political willingness is required from all Governments and political parties to support people with disabilities, and this means amongst other things, a greater commitment to adequate funding.