Cerebral Palsy
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Cerebral Palsy Australia

Submission to

Disability Care and Support Inquiry Australian Productivity Commission

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Introduction

Cerebral Palsy Australia welcomes the opportunity to present a submission to the Australian Productivity Commission Inquiry into a national Disability Care and Support Scheme and commends the initiatives relating to this Inquiry. In Australia, the current systems which attempt to support people with disabilities, their families and carers, are inadequate, inequitable and crisis driven.

This submission from ***Cerebral Palsy Australia*** does not attempt to address all the questions in the Australian Productivity Commission Issues Paper (May 2010). Rather, this submission wishes to support the submissions of our Member Organisations (in which most of these questions are addressed) and to emphasise particular issues relevant to children and adults with Cerebral Palsy, their families and carers.

Cerebral Palsy is the most common cause of physical disability affecting children in Australia and most developed countries (Howard, Soo, Kerr Graham, Boyd, Reid, Lanigan, Wolfe and Reddihough: 2005). An estimated 30% of people with Cerebral Palsy have severe forms and are non-ambulant and at increased risk of pain and poorer health (Donnelly, Parkes, McDowell and Duffy: 2007). Cerebral Palsy is a condition which may result in an individual having multiple impairments and significant lifestyle limitations (Odding, Roebroeck and Stam: 2006).

To place this submission in context, the following is a statement from the Canadian Paediatric Society (2000):

> “The World Health Organization defines a child with multiple impairments as a child with a significant disability combined with a sensory and/or cognitive disability. Such a child places tremendous stress on a family because of the many associated issues and the fact that, in most cases, the child has a chronic condition with no cure. Ongoing support is crucial to these families; they incur increased expenses, which are aggravated frequently by the loss of income. Family life becomes more isolated.....the parents of a child with multiple impairments face a recurring series of stresses.”

About Cerebral Palsy Australia

Cerebral Palsy Australia is the national peak body of Member Organisations that deliver services to people with Cerebral Palsy and people with similar disabilities and their carers. Since 1952, ***Cerebral Palsy Australia*** (formerly known as CP Australia and the Australian Cerebral Palsy Association) has provided a national focus for disability awareness, fundraising and service development for children and adults with Cerebral Palsy.

The Member Organisations of ***Cerebral Palsy Australia*** include diverse organisations from each state and territory. These are:

- Carpentaria Disability Services, located in the Northern Territory
- Cerebral Palsy League of Queensland
- Cerebral Palsy Support Network, located in Victoria
- Cerebral Palsy Tasmania
- Community Accommodation and Respite Agency (CARA), located in South Australia
- Cootharinga Society of Northern Queensland
- Leveda Inc located in South Australia
- Northcott Disability Services, located in New South Wales and the ACT
- Novita Children's Services, located in South Australia
- Scope (VIC) Ltd
- Spastic Centres of South Australia Inc (SCOSA)
- The Centre for Cerebral Palsy, located in Western Australia
- Yooralla, located in Victoria.

The combined operational budget of all ***Cerebral Palsy Australia*** Member Organisations is well in excess of $300 million. The Member Organisations provide services to children and adults with Cerebral Palsy and similar disabilities. Services include accommodation, respite, day options, employment, therapy, equipment prescription and manufacture, community access and community development.

Many of our Member Organisations also undertake specific projects, carry out research and conduct training. Some foster the development of services for people with Cerebral Palsy and similar disabilities in countries such as East Timor, Fiji, India, Thailand, Cambodia and the Marshall Islands.

Membership of ***Cerebral Palsy Australia*** enables organisations to formally participate, directly or indirectly, in a national body working to enhance people's lives. Member Organisations benefit from being linked to a network committed to mutual support and information sharing through regular updates, meetings and conferences.

Until recently ***Cerebral Palsy Australia*** has been an Incorporated Association. In May 2010 ***Cerebral Palsy Australia*** became a Company Limited by Guarantee. This change is in response to the increasingly challenging and complex environment in which ***Cerebral Palsy Australia*** functions. This move to a Company Limited by Guarantee will ensure that ***Cerebral Palsy Australia*** is well positioned to support our Member Organisations across Australia in their work for children and adults with Cerebral Palsy, their families and carers.

Since being established in 1952 ***Cerebral Palsy Australia*** has worked to promote and advance the rights, welfare and social inclusion of people with Cerebral Palsy. Our key purposes are:

- assisting in obtaining appropriate funding and support for organisations working with people with Cerebral Palsy and their carers
- supporting and encouraging innovation and improved service practices
- encouraging, conducting and supporting research concerning Cerebral Palsy
- working with governments in developing policies for services and support of organisations working with people with Cerebral Palsy and their carers.

Taking into account the purposes *of* ***Cerebral Palsy Australia***, all our Member Organisations welcome this opportunity to provide a submission to the 2010-2011 Inquiry of the Australian Government Productivity Commission relating to Disability Care and Support. It should be noted that most of our Member Organisations have forwarded a submission to the current Australian Productivity Committee Inquiry and / or have contributed to other submissions.

Cerebral Palsy Australia requests that the Inquiry notes particularly the submissions forwarded by some of our major Member Organisations:

- Cerebral Palsy League of Queensland
- Northcott Disability Services, located in New South Wales and the ACT
- Novita Children’s Services, located in South Australia
- Scope, located in Victoria
- The Centre for Cerebral Palsy, located in Western Australia
- Yooralla, located in Victoria.

Guiding Principles of a Reformed System

Cerebral Palsy Australia is supportive of the concept of a National Disability Care and Support Scheme. The current system is inadequate and, to quote the submission of our Member Organisation, ***Northcott Disability Services*** (2010):

> “Despite significant progress, improvements and initiatives to address issues in the system, there are still insufficient resources to meet needs and gaps in services; there also remains inequity in access to services, and people with a disability have limited control and choice in planning their own supports and having certainty about their future and how their needs will be met.”

Cerebral Palsy Australia acknowledges and affirms the Terms of Reference for this Productivity Commission Inquiry into Disability Care and Support and especially notes the following:

> “The Australian Government is committed to developing a National Disability Strategy to enhance the quality of life and increase economic and social participation for people with disability and their carers.”

> "There remains a significant level of unmet demand for disability services which impacts upon the lives of people with disability, their families and carers. Demographic change and the anticipated decline in the availability of informal care are expected to place further pressure on the existing system over the coming decades."
>
> "…there is currently no equivalent entitlement to disability care and support services."

Having considered the Terms of Reference of this Inquiry, ***Cerebral Palsy Australia*** supports the views of the National Disability and Carers Alliance (July 2010):

> "Our vision is an Australian society that ensures the full and equal social, economic, cultural and political participation of people with a disability, their families and carers."

Cerebral Palsy Australia supports the five Guiding Principles presented by the National Disability and Carers Alliance (July 2010):

- Commitment to the realization of the rights enshrined in the UN Convention on the Rights of Persons with Disabilities
- Equity
- Self Determination
- Efficiency and Effectiveness
- Sustainability.

Cerebral Palsy Australia commends to the Inquiry the proposed **Guiding Principles of a Reformed System** included in the submission of our Member Organisation, ***Cerebral Palsy League of Queensland***. These Principles are:

1 ***Universal access*** - all Australians with a disability eligible to access the system will have access to appropriate supports and services to meet their level of support need and "no wrong door". A National Disability Insurance Scheme will be enshrined in the National Disability Strategy, signed by all levels of government in Australia.

2 ***Equity*** - across disability groups, geographic boundaries, socio-economic groups and cultural and language divides.

3 ***Sustainable*** - people will have confidence that they will receive the support they need without resorting to "creating" a crisis to be eligible. This approach also implies ***flexibility*** throughout a person's life. At times requiring less support and able to "relinquish" hours knowing that in future times when more may be required it will be there.

4 ***Invest in a transition phase*** – building the capability and capacity of Australians with a disability and their families to operate as informed, assertive purchasers. Ensuring sufficient numbers of service providers are prepared and organised to compete in an open market so that clients continue to have choice and a guarantee of quality safe services where needed.

5. ***Invest in a transparent service system*** - across all jurisdictions where quality can be assured and tested and where a robust independent complaints mechanism exists.

6. ***Investment in people with a disability*** - support needs to be person-centred and strengths-based, measured through improvements in an individual's or family's key socio-economic indicators such as education levels, life expectancy, income levels, home ownership etc.

7. ***Invest in early intervention*** - invest both at early points in a person's life-stages; and as soon as practicable once a disability or situation has occurred to improve outcomes for the individuals and to reduce total government outlays in areas such as health, social justice, housing etc.

8. ***Human rights*** - are protected as a fundamental cornerstone of government policy and practice.

9. ***Invest in inclusive communities*** – where Australians with a disability do not encounter physical, attitudinal or systems barriers to contributing to their communities of choice as citizens.

10. ***Consistent nationally*** – with supports being portable across all Commonwealth, State and Territory jurisdictions.

What is Cerebral Palsy?

Cerebral Palsy is a disorder of muscle control and is caused by damage to, or lack of development in a part of the brain that controls movement. There is no cure and in many cases the cause of Cerebral Palsy cannot be identified (Sydney Children's Hospital Randwick: 2009). The developing brain may be damaged by exposure to infections during pregnancy or infancy. Other causes include bleeding in the brain, lack of oxygen or a brain injury shortly after birth. There are also some rare inherited conditions. The Centre for Developmental Disability Health (CDDH Victoria) notes that causative events include:

- Prenatal (75% of cases) e.g. developmental brain anomalies
- Perinatal (8-10%) e.g. birth asphyxia
- Postnatal (10%) e.g. accidental injury, severe brain infection.

As noted in the *Kids Health Information* published by the Royal Children's Hospital (RCH Melbourne: 2007) Cerebral Palsy causes problems with motor control and co-ordination. This may result in weakness, difficulties with balance, stiffness, slowness and awkwardness. The physical conditions of Cerebral Palsy vary considerably amongst children and adults and there may be impacts on:

- One arm or leg (monoplegia)
- One side of the body (right or left hemiplegia)

- Lower limbs (diplegia)
- Both arms and legs and the trunk (quadriplegia).

The Australian Institute of Health and Welfare Report (2006) emphasises that the severity of disability associated with Cerebral Palsy is highly variable, depending on which limbs are affected and the type of impairment. The most common impairment of people with disability is abnormal muscular control or spasticity (increased muscle tone). Other impairments include dyskinesia (involuntary movements); ataxia (abnormality of muscle coordination) or hypotonia (diminished muscle tone).

As well as difficulties with mobility, posture and balance, children with Cerebral Palsy may also have difficulties with speech, hearing or vision, epilepsy, intellectual or learning difficulties, perceptual difficulties, gastro-oesophageal reflux, orthopaedic problems, constipation, feeding difficulties, saliva control problems or repeated chest infections. Some children who have severe physical disabilities associated with Cerebral Palsy may have completely normal intelligence. Other children may have intellectual disabilities as well as physical. (RCH Melbourne: 2007).

For children with Cerebral Palsy, early diagnosis, early intervention and access to appropriate services are essential to enable the best outcomes and to enable children with Cerebral Palsy to reach their full potential. For adults, fatigue, loss of physical function and independence occurs earlier than in the mainstream ageing population.

Cerebral Palsy: Prevalence and Costs

Cerebral Palsy is a permanent condition. It is the most common physical disability in childhood and there is no known cure (McIntyre, Novak and Cusick: 2009). An Access Economics Report (2008) states that around 600-700 infants are born with Cerebral Palsy each year in Australia. It is estimated that in 2007 there were 33,797 Australians with Cerebral Palsy. This number is projected to increase as the population grows (to around 47,601 by 2050), being about .2% of the population.

The Access Economics Report (2008) considered a variety of sources when estimating the costs associated with Cerebral Palsy. The Report notes the following:

- In 2007 the financial cost of Cerebral Palsy was $1.47 billion (0.14% of GDP)
- Additionally, the value of the lost wellbeing (disability and premature death) was a further $2.4 billion
- In per capita terms this amounts to a financial cost of $43,431 per person with Cerebral Palsy per annum
- Including the value of lost wellbeing, the cost is over $115,000 per person per annum

The Access Economics Report (2008) also stated:

> "Individuals with CP bear 37% of the financial costs, and their families and friends bear a further 6%. Federal government bears around one third (33%) of the financial costs (mainly through taxation revenues forgone and welfare payments). State governments bear under 1% of the costs, while employers bear 5% and the rest of society bears the remaining 19%. If the burden of disease (lost wellbeing) is included, individuals bear 76% of the costs.
>
> Compared to other health conditions, CP is:
> - More common in any year than the most common types of cancer, stroke, eating disorders, appendicitis or road traffic accidents
> - In the top five most costly conditions on a per capita basis of 15 conditions studied by Access Economics in recent years; and
> - A condition with a higher disability burden than being blind, deaf, having severe asthma or diabetes. CP is also more disabling than having heart failure, localised cancer or the most severe forms of Attention Deficit Disorder with Hyperactivity (ADHD)."

Current Realities for Individuals, Families and /or Carers

Irrespective of age, the health issues associated with Cerebral Palsy are extremely complex so there are ongoing difficulties for whole of life, not only for the individual but also for families / carers. As well as supporting the submissions of our Member Organisations, ***Cerebral Palsy Australia*** wishes to emphasise some particular issues which need to be acknowledged and addressed in the planning for the proposed national Disability Care and Support Scheme.

(a) Unmet Need: Services, Equipment and Transition Phases

The Australian Institute of Health and Welfare (AIHW) Report (2006) considered the need for assistance with core activities (self-care, mobility and communication) and noted that people with Cerebral Palsy and Cerebral Palsy-like disabilities are more likely to need very frequent assistance with core activities. As well as needing significant care support, the Report noted the importance of 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."

Despite this importance, the AIHW Report (2006) noted substantial levels of unmet need in relation to therapy and equipment. The submission to the Productivity Commission Inquiry from our Member Organisation ***Novita Children's Services*** (2010) stresses that

> "…therapy and equipment are critically interrelated in successfully supporting mobility and independence as well as enhancing capacity to participate in the community."

Yet, the ***Novita Children's Services*** (2010) submission also notes:

> "Under the current arrangements the provision of equipment across jurisdictions is often sporadically funded, there are huge waiting lists, and as a consequence, the ability to achieve social inclusion is often denied."

These needs relating to ongoing care, therapy and equipment result in substantial emotional, social and financial impacts on people with Cerebral Palsy, their families and carers. The Access Economics Report (2008) emphasises that the likelihood and severity of associated impairments increase with the severity of motor impairment for people with Cerebral Palsy. Having a number of impairments requires a range of therapies and diverse equipment, decreases quality of life of the individual with disabilities and places significant and constant social, emotional and financial demands on the families / carers who have to battle through a frustrating and woefully inadequate and inequitable system.

Regarding aids and equipment, Shut Out (a consultation report prepared by the National People with Disabilities and Carer Council in 2009), states

> "Elsewhere in the world, people with disabilities have a legislated right to the aids, equipment and technology they require for daily living. No such right exists in Australia.
>
> …people with disabilities and their families, friends and carers find it incredibly difficult and sometimes impossible to access the aids and equipment essential to daily functioning.
>
> Lack of availability or lengthy waiting periods forces people with disabilities and their families into purchasing aids and equipment themselves, often at considerable expense. When beyond the budget, people with disabilities are forced to go without for extended periods of time. Either way, the quality of life of people with disabilities and their families is significantly compromised."

Unmet need is not only an issue with therapy and equipment but also occurs during vital points of transition. Our Member Organisation, ***The Centre for Cerebral Palsy (TCCP)*** in Western Australia interviewed client families for the purposes of their submission to the Productivity Commission Inquiry. The submission notes:

> "… unmet and under-met demand is greater in programs relating to critical transition points. These are programs relating to school commencement, transition from primary to high school and transition from school to employment or alternatives to employment and independent living options."

Access to mental health services and respite were also identified as other key areas of unmet demand. As well, ***The Centre for Cerebral Palsy*** emphasises the limited services available to Aboriginal people, particularly those residing in rural and remote areas. The submission notes that despite indigenous people comprising 3.8% of the population of WA, Aboriginal children made up 8.4% of children born with Cerebral Palsy between 1980 and 1999.

(b) Eligibility and the need for ongoing support

As stated in the submission from our Member Organisation, ***Scope***:

> “Scope believes that Australians with a severe or profound disability need increased funding and support to engage with their community, get a job where possible, and live a happy and meaningful life. Establishing an entitlement based, fully funded social insurance Scheme to provide long term care and support for Australians with a severe or profound disability will provide greater certainty for the future for people with disabilities (PWD) and their families.”

The ***Scope*** submission also emphasises the importance of recognising the needs of those who have life long conditions so will require life long, ongoing support. ***Scope*** states:

> “That funding and actuarial modelling recognize and make funding provision for the fact that, unlike other personal injury compensation schemes which have a rehabilitation and recovery focus, the levels of funded support will generally not diminish (and in many cases may increase) over time, particularly for people with cerebral palsy and like conditions.”

The submission from our Member Organisation, ***Northcott Disability Services***, contains some case studies which highlight current inequalities and gaps in funding that adversely impact on ***Northcott*** clients. People may have the same injury but different entitlements to funding support because of the circumstances of their injury. These inequitable circumstances experienced by individuals and their families / carers are also noted in the submission from Professor Dinah Reddihough and Dr Jane Tracy (2010). To quote;

> “We have seen some families receive large compensation payouts that enable their sons or daughters to have a high standard of care, equipment, accommodation, respite, and recreation options – while others, with the same level of disability, struggle to arrange and pay for the most basic equipment, live in substandard accommodation without the required home modifications, and have few opportunities for choice, independence and community participation in their lives.”

The extensive impacts of inequalities in the current system are also emphasised in the submission of our Member Organisation, the ***Cerebral Palsy League of Queensland***. These inequalities result in people receiving different levels of support and care and this is dependent on "…how, when and where their disability was acquired." These issues of eligibility and resulting inequalities adversely impact on families and carers across Australia so must be addressed and resolved.

(c) Demands on Families / Carers and the Need for Respite

The extreme demands on families / carers have been emphasised in many recent reports. Submissions to the Shut Out (2009) report comprehensively demonstrated:

> "…the experience of caring for someone with a disability is often a lonely one. Family, friends and other carers reported feeling abandoned by both government and the community and felt there was too little support for their all-important role. Many expressed frustration that they alone were left to fill the gaps in the service system."

A research paper from the Australian Institute of Family Studies (2008) contains significant data emphasising the higher rates of mental health problems amongst carers and poor physical health. Families who cared for a person with a disability were more likely to experience a higher level of financial hardship than the general population. The report also outlines the substantial social / emotional costs associated with caring and this issue is also emphasised by Bonyhady (2009)

> "Amongst carers who provide informal care full time and are in receipt of Carer Payment only 11 per cent work part-time. Then, in more than 50% of cases when they are no longer eligible for Carer Payment, they shift across to other forms of government income support, because either long term disengagement from the workforce or the onset of physical disabilities or mental illness due to their caring role have made them unfit for work. This is a huge cost to society."

Submissions from our Member Organisations also emphasise the critical aspects of the cost of caring for people with disabilities and the urgent need to support families and carers. The present arrangements with the huge dependence on family and informal carers cannot be sustained and represents a significant unfunded liability in Australia. To quote the submission from our Member Organisation, ***Yooralla:***

> "Yooralla wishes to note that there are significant benefits to the entire Australian community flowing from a long-term disability care and support scheme. Needs based response to the care and support needs of people with disability will:
>
> - release family carers into the workforce, delivering productivity and taxation gains to the entire community
> - reduce the adverse effects of prolonged intense caring, improving health and economic outcomes for family members and in turn reduce community health care costs

- increase employment opportunities for people with disability, delivering health care costs and economic benefits."

The submission from our Member Organisation, the ***Cerebral Palsy League of Queensland***, acknowledges the contribution of unpaid families / carers and the daily struggle to obtain services and support. To quote:

> "Barriers to active workforce participation and an income support system that does not address the additional cost of disability leave the majority of households, in which a person with a disability lives, with disposable income levels well below their peers in the broader community. This means that the capability and capacity to purchase mainstream or generic support solutions is greatly reduced for these households. This in turn leads to greater need for or reliance on specialist formal supports, which ironically for the majority of households, do not exist."

A direct impact on family quality of life is the availability of respite which supports families / carers, enabling them to maintain community links and be actively employed. Significant reports and data have emphasised the urgent and ongoing need for respite including the AIHW (2006) and the Shut Out report (2009) which states:

> "Many people with a disability continue to depend on family carers as their main source of support. There is a lack of facility-based respite available for parents and carers of people with a disability and carers are at risk of suffering physical and mental health problems if adequate supports are not put in place to enable them to effectively care for their relatives. A flexible and affordable range of options needs to be made available to carers as a matter of urgency."

The lack of centre based respite in regional and rural areas is also of significant concern.

(d) Individualised Funding

Individualized funding is a way of organizing consumer-directed care that has been introduced in most Western European countries and parts of North America (Fisher et al 2010). ***Cerebral Palsy Australia*** supports individualised funding but acknowledges the importance of establishing different models of operation in order to accommodate the diverse needs and circumstances of individuals with disabilities and their families / carers. This need for diversity in models is noted in the submission of our Member Organisation, ***Northcott Disability Services:***

> "Northcott is comfortable with a range of individualized funding models, as long as there are a range of models available which are flexible and adaptable to meet the needs of people with a disability. Northcott also recommends that there should be models of funding other than individualized funding packages available under the

> scheme, to enable people with a disability to choose the model that is most appropriate for them and would best meet their needs."

Also of vital importance with individualised funding is the issue of monitoring and review. The submission of our Member Organisation, ***Scope***, states:

> "Where recipients choose to establish individual funding agreements, it is important that the monitoring and auditing processes be established to mitigate any risks of mismanagement of the funding whilst acknowledging the rights and responsibilities of persons with a disability."

This same issue is raised in the submission by our Member Organisation, ***Cerebral Palsy League of Queensland***. The submission notes that if people take full responsibility for managing funds, training and safeguards will be required. Regarding individualised funding, our Member Organisation, ***The Centre for Cerebral Palsy (TCCP)***

> "..recognises that a considerable investment would need to be made in information, resources and advocacy to ensure that individuals, carers and families have the capacity to make informed choices. TCCP also recognises that all families are not the same, and that some would require more assistance than others prior to being able to make choices."

A paper by Carers UK (2008) focuses on the carers' experiences of direct payments and also emphasises the need for back up and support. The submission by our Member Organisation, ***Northcott Disability Services***, also strongly supports individualised funding but raises significant questions about potential risks and negative impacts for individuals with disabilities, their families / carers. Such risks and potential problems may include lack of knowledge, lack of available services, inappropriate advice from service providers and inappropriate allocation of funds by the individual and / or family.

There will also be significant implications for service providers. The submission of our Member Organisation, ***Yooralla***, stresses the importance of the proposed scheme establishing and implementing transition arrangements which will enable disability support providers to move from operating under a 'block funding' model to an 'individualised funding' model.

(e) Workforce and Training

Crucial to the proposed developed of a National Disability Insurance Scheme is the developed of a disability workforce and training strategy to ensure the provision of staff with appropriate skills and competencies. Our Member Organisations have acknowledged the difficulties associated with attracting and maintaining direct care and health professional staff, especially therapists. ***Novita Children's Services*** notes:

> "Lack of workforce capacity to meet the demand for disability services, in particular the recruitment and retention of staff, is also a key concern for ***Novita*** and is a common issue for many non-government disability services providers. It will be critical for the NDIS to recognise and address the challenges created by a labour shortage and limited funding to meet market level remuneration."

Northcott Disability Services also notes remuneration issues and the lower pay rates offered in nonprofits with government services paying higher salaries for the same positions. This makes attracting staff difficult.

The submission from ***Yooralla*** stresses that any new scheme must acknowledge that the costs of employing workers is the main component in the provision of services to people with disability. ***Yooralla*** states:

> "A critical component for people with disability to have a quality life is having access to well-trained and regular support workers. Therefore, *workforce training, development and retention* must be an important feature of any new scheme.**"**

Yooralla also raises the issue of remuneration, disparities between pay rates across services and the competition from the retail and hospitality sectors which attract workers from the disability sector. The ***Cerebral Palsy League of Queensland*** stresses that an ageing workforce compounds the problems and these challenges are even more complex in regional and rural areas where travel expenses contribute significantly to the cost of providing services.

There is a need to build on the KPMG (2006) report which considered disability workforce capacity issues and to respond to the looming workforce crisis facing the disability sector as noted by National Disability Services SA (2010) submission to the Inquiry. Our Member Organisation, ***Scope*** suggests the development and implementation of a disability workforce strategy which should include workforce analysis, development of career paths, training and competencies and increased workforce flexibility. ***Scope*** also notes that a high proportion of work is performed under distant, intermittent supervision.

> "This is particularly evident in the delivery of specialist services in rural and remote areas. The opportunity exists for the establishment of hub and spoke support models that support staff to provide quality services in remote areas. Such approaches can be applied to direct support workers (attendant care staff) to develop skills in manual handling, working with clients with cognitive disabilities and developing active support strategies to name a few examples. For low incidence, specialist responses a similar model can be highly effective in delivering information, advice and technical support to local professional staff."

Scope's Communication Resource Centre currently implements this model and provides highly specialised, state wide support to people with complex communication needs.

(f) Early Intervention

Early Intervention is of vital importance and this is addressed in the submissions of our major Member Organisations. The ***Scope*** submission states:

> "Early intervention with young children and people with a recently acquired disability is demonstrably cost effective in reducing long term care and support needs. Early intervention with people with deteriorating conditions can reduce the risk of injury (for example, by delivering timely and appropriate home modifications) and break down of the family relationships."

The current system tends to be reactive and crisis driven. Proactive investment in high quality early intervention for both children and adults may reduce dependence on support services in the longer-term. The ***Cerebral Palsy League Queensland*** stresses the importance of early intervention for children, resulting in better personal outcomes, social inclusion and decreased dependence on government funding. The ***Novita*** submission emphasises the importance of equity and consistency of access to Early Intervention Services but notes:

> "Lengthy gaps exist between referral for early intervention, assessment and action. Delays are frequently in the order of one to two years, by which time the diagnosis may have changed and the original need for the service is superseded by another need…"

Another issue relating to Early Intervention Services is the fragmentation that may occur between services (government, non-government and private) and waiting periods. The submission of our Member Organisation, ***Yooralla,*** notes the importance of maximising long term skill development

> "Access to early intervention support and services is critical for every child who is not meeting critical developmental milestones. Yooralla believes that it is far better to err on the side of providing supporting to all children in this situation and risking the provision of support to a child who may not have a long term disability, than to wait until a formal diagnosis is made. Waiting may lead to longer term skills deficits that might have been addressed more successfully with an early intervention program."

Concluding Comments

Ms Diana Heggie (President of ***Cerebral Palsy Australia***), would be pleased to speak at future hearings. A person with Cerebral Palsy and associated with one of our Member Organisations would also be available to speak to the Inquiry. ***Cerebral Palsy Australia*** appreciates the opportunity to forward this submission to the 2010 Australian Productivity Commission Disability Care and Support Inquiry. Enquiries to Barbara Kitchen (Executive

Officer of ***Cerebral Palsy Australia*** and author of this submission): Tel: 03 9843 3069 or email to bkitchen@cerebralpalsyaustralia.com

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