Cerebral Palsy
ALLIANCE
Formerly known as The Spastic Centre

Submission by Cerebral Palsy Alliance to the Productivity Commission on Disability Care and Support: Draft Inquiry Report

Cerebral Palsy Alliance welcomes the recommendations of the draft report and offers comments, suggestions and information, particularly in relation to the needs and issues of people with cerebral palsy.
The scheme should be fully funded on an entitlement basis for those who meet eligibility criteria. The funding model will also need to take into account any unintended consequences of a market driven approach to service delivery. Providing services to some client groups and some localities will be more expensive; to maintain viability for service providers endeavouring to meet the needs of these clients, a combination of individualised funding and block agency funding may be appropriate. This will particularly be the case for some rural and remote clients.

CHAPTER 3 WHO IS THE NDIS FOR?

Tier 1.

Cerebral Palsy Alliance supports the objective of:

creating awareness by the general community of the issues that affect people with a disability.

Attitudinal change is needed to address stereotyping that results in social isolation and restriction of opportunity.
One strategy to achieve this is education of primary school children. Cerebral Palsy Alliance has for the past five years delivered a disability awareness educational program to primary school students in NSW. This has been mapped to the education curriculum and is delivered by volunteers and a person with a disability over two, ninety minute sessions.

A research evaluation has shown the efficacy of this program in increasing knowledge and changing attitudes.

Recommendation 3.2

- We suggest that further clarity is required in relation to intellectual disability. The report implies automatic eligibility for NDIS, regardless of the level of disability and the cost of support.
- Specifying one disability group over another as automatic criteria for inclusion may be problematic.
- *Significant* disability can be partly but not solely explained by diagnosis or severity of impairment. Some associated impairments will load the significance of need e.g. (Gross Motor Function Classification Scale (GMFCS) 5+ Intellectual Disability + Epilepsy.
- How will “reasonable potential for needing cost effective early interventions” be assessed? Children assessed as being *at risk* of cerebral palsy should be included; as with intellectual disability, as there is sufficient research to show that early intervention makes a difference.
- There is a need to clarify to what age in children the early intervention period extends. Similarly for adult onset disabilities, what period of time post onset will be deemed early intervention?
- “have large identifiable benefits from support” is very subjective and open to wide interpretation, given that it can only be assessed post support.

Recommendation 3.4

- Disability services can play an important role in prevention, early intervention and treatment for mild-moderate mental health needs of clients/carers (e.g. depression, stress, anxiety, adjustment, grief and loss, disorders of childhood e.g. autism). Mental health services can better respond to acute, severe and chronic mental health needs especially mood disorders, psychosis, substance abuse, eating disorders etc.

- Collaboration between disability and mental health services can lead to appropriate and more timely identification of mental health needs that may otherwise be subject to diagnostic overshadowing e.g. supporting clients with complex communication needs. Accessing health, mental health, and palliative and aged care sectors need not be mutually exclusive of the disability sector.
- Collaboration with the Health sector will also be very important. Currently the rehabilitation departments of major hospitals are focussed on the health and functional needs of people with disabilities. The intersection of the medical model with disability model for people who have disabilities (but are not sick) is already problematic. I think any MOUs will need not only to include protocols for referrals but also division of responsibilities.

Recommendation 3.5

- It is unclear if a person can transfer their NDIS funding into the aged care sector and also attract funding from this sector. Experience has shown that the aged care sector is unable to sufficiently meet high needs care of ageing people who have a lifelong disability. Although many people also experience disability in their old age, this disability is often associated with the ageing process. People with disability experience a compounding effect of their lifelong disability on top of what they also experience a natural outcome of growing old, so funding should be reassessed prior to transfer to the aged care sector.
- There is a preference for many people with a disability to age in place. An NDIS should take this into account.

Recommendation 3.6

- After the pilot phase, is there a staged plan for applying the scheme retrospectively to all those with existing disability? This will be a major task not only in terms of assessment but also for assessing the impact on sector change for providers who are currently supporting these individuals.

Recommendation 3.7

- What consideration been given to how ‘forward looking’ assessment will be? Will assessors consider the lifespan or specified time periods?
- We support the use of the ICF as a framework for needs assessment, along with a holistic and forward looking approach that encourages realistic goal setting.
- We need an assessment tool that has a focus on severity of impact rather than severity of diagnosis; certainly for Cerebral Palsy, tools such as the Gross Motor Function Classification System (GMFSC) and Manual Ability Classification System (MACS) can help us predict severity of impact. We need tools that match up with impact on all life domains.
- A tool that balances objective evaluation of severity of need and subjective perception of need may have merit, particularly when considering the variability in client and family situation, coping strategies and resilience.

CHAPTER 4 WHAT INDIVIDUALISED SUPPORT WILL THE NDIS FUND?

Recommendation 4.3

- A modest upfront contribution will be hard to introduce if the scheme is not means tested as is suggested, as not everyone will have capacity to pay.
- If unpaid care is taken into account at the time of assessment, what happens when this support changes? There may be a need to respond quickly to a change in circumstances.

Recommendation 4.4

- Evidence is not always available for all interventions; many are provided based on insufficient research simply because insufficient research funding has been invested in the area. We suggest an approach that only excludes interventions known to cause harm and those that make extraordinary claims for cure and prevention when this is known not to be possible.
- In the absence of consistent use of a framework for evaluating benefits/efficacy of services, how will this be monitored? (i.e. not everyone is using NHMRC or similar framework for appraising evidence). This point does not seem to take into account that ‘benefit’ will be a very subjective construct and even a therapy that yields no benefit in terms of changing an underlying condition or improving function, can still be perceived by a consumer as beneficial.

CHAPTER 5 ASSESSING CARE AND SUPPORT NEEDS

Recommendation 5.1

- We support the development of plans that build in an individual’s aspirations however aspirations require some context and reality check for capacity and response. For example, there are known trajectories for development with different levels of disability e.g. a child who is GMFCS 5 (Gross Motor Function Classification Scale) will never walk independently although sometimes it is the aspiration of the parents for their chid to walk and belief that more physiotherapy will eventually achieve this milestone. Funds could be misdirected and poorly spent on an outcome for which there is no evidence. Balancing evidence with aspiration will be an important issue for the assessment process.

Recommendation 5.2

- The emphasis on medical information is of concern; this is not the only source of important information for assessment.
- Willingness to provide unpaid family support is dependent upon a number of factors that need to be in place for sustaining the family. If and when these breakdown, reassessment in a timely way will be essential. Some families may feel guilt or distress if they are unable to provide adequate care and this will need to be sensitively handled.
- We are unclear about the comment of the NDIA being responsible for judging the efficacy of interventions – this is a very large responsibility and is very complex. What capacity will there be to test efficacy through research?

Recommendation 5.4

- There does not appear to be an obvious process for a person or family contesting the outcome of the assessment process completed by NDIA.
- Will there be any scope for the person themselves or their family to initiate a request for a reassessment of need for funded support prior to a scheduled review? e.g. a change in functional ability that does not coincide with a key transition point.

Recommendation 5.7

- We support the use of the ICF as a framework, along with a holistic and forward looking approach that encourages goal setting to support social and economic participation.
- Service coordination is critical especially for those with moderate to severe needs.

CHAPTER 6 WHO HAS THE DECISION MAKING POWER?

Recommendation 6.1

- Some very high risks are associated with cashing out funds for self- directed packages if this is not used wisely, given that the level of reporting and accountability suggested for this model is proposed to be less than for service providers. What is the fall back position for those for whom the money has run out?
- If the reporting is less, how will the outcome data be captured?

Recommendation 6.3

- Banking 10% of the annual allocation may not be sufficient to allow for the purchase of equipment. Children and adults with severe and complex cerebral palsy will commonly need multiple pieces of equipment during their lifetime. The Cerebral Palsy Alliance Equipment Register annually records a need of $3.4 million. This represents 650 pieces of equipment which are required by 400 people. We estimate that this represents one quarter of the equipment needs of people with cerebral palsy in the state. Our register also monitors the State Government response to this need. Of the $3.4 million needed, $1.5 million was funded by government. The waiting time was usually 6-18 months.

Recommendation 6.4

- Should read “care is intermittent and provided by a non household family member”, not a non resident family member as this has connotation about Australian residency.

Recommendation 6.5

- There is a perception that family members are valued less than paid carers and the discount of 20% perpetuates this notion.

Recommendation 6.6

- There will be a need for training and counselling for parents/carers/individuals that use self directed funding. Training topics could include personal care, lifting, behaviour, planning, transport, managing funding, financial planning, recruiting/selecting workers, and interventions.

Recommendation 6.8

- Investigation of complaints should be at arms lengths from the NDIA.
- How can people demonstrate their capacity to mange funds well if they have no previous experience of doing this?

CHAPTER 8 DELIVERING DISABILITY SERVICES

Recommendation 8.1

- We have concern about the statement relating to the monitoring of “well being”; there will need to be some social assessment framework to able to do this effectively.

Recommendation 8.3

- Plans to encourage innovation need to include components for training + mentoring + knowledge management tools.

Recommendation 10.2

- The qualitative trends that emerge through exploration of client/family needs and experiences within the disability sector will be important in informing the research agenda.

Recommendation 13.1

- We have concern that the Commission is making a recommendation of no minimum qualifications for disability support workers. There is quite a difference for individuals privately employing a worker and a service provider employing workers.
- There is a need for minimum standards for workers, especially when the sector has an expectation that workers further develop advanced skills such as person centred planning, coaching/communication skills, working within a best practice framework, OHS, legal/ethical framework, duty of care.
- It is important to also clarify the difference between qualifications and core competencies. Although acknowledging some “on the job training” as important and qualifications being helpful for providers to attract/recruit it doesn’t really acknowledge the system of support=minimum qualification + competency based training + supervision + personal attributes.

- Qualifications for the sector also provide the staff with opportunity to move within the sector or advance their careers. The key is not creating barriers but supporting workers to attain the qualifications. This will give some sort of regulation to a sector that is really unregulated; it needs to move forward like the child care sector.

- We support the continuation of subsidising training for workers.

- A low level of literacy can also be a major barrier to work. Service providers who can support literacy can tap into a group of workers that can make great carers e.g. Tibetan community. The barrier is not a qualification but language and literacy support; this is another area where increased training subsidies to service providers could assist.

- Recruitment of therapy staff from overseas would be facilitated if the Australian Physiotherapy Association would consider a less stringent process for registration for physiotherapists from USA, Canada and UK.

Given the complexity of the implementation process, we suggest that the trial phase takes place in multiple locations, at least one in each state and territory, to allow testing in the different environments.

Thank you for considering this submission.

Yours sincerely

R White

Rob White
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