

NDIS Review Secretariat

Department of the Prime Minister and Cabinet
PO Box 6500
Canberra ACT 2600

Re: Submission to the NDIS Review August 2023

Dear NDIS Review Secretariat,

On behalf of Cerebral Palsy Alliance, I present a submission to the NDIS Review. Our short submission acknowledges the extensive work undertaken to date.

An estimated 34,000 Australians have cerebral palsy. It affects 1 in every 700 births and is caused by a brain injury during pregnancy or shortly after birth. Cerebral Palsy Alliance is committed to positively changing the lives of people with cerebral palsy and other neuro-developmental disabilities. With more than 75 years of deep expertise and experience, we have been pioneering treatments, harnessing and accelerating technology and leading global research efforts to change the lives of these individuals – a global community of over 17 million with cerebral palsy and associated community of 350 million.

Our global research vision, to enable the world’s best cerebral palsy experts to find ways to prevent and treat cerebral palsy, is led by the Cerebral Palsy Alliance Research Institute, established in 2005. It is the world’s largest dedicated cerebral palsy research organisation, with 4 of the top 10 experts in the field and over 145 academic papers published since 2020. The CPA Research Institute has significantly contributed to the drop in the rate of cerebral palsy by over 40% in a generation.

A recently published paper by the CPA Research Institute warrants awareness raising to the NDIS Review given its focus area – out of pocket costs for people with cerebral palsy in Australia. We believe this fits in the 10 areas of improvement outlined specifically:

- Applying and getting a plan,
- A complete and joined up ecosystem of support,
- The support and service marketplace, and
- Help accessing supports.

This research highlights the disproportionate financial challenges faced by people with cerebral palsy. People with more severe cerebral palsy experience even greater challenges and costs. A focus on reducing the severity of this condition, or reducing its prevalence, would make a material difference for our economy and in the day to day lives of people with cerebral palsy and their families and is a solution for the Review to consider.

The research study [**‘Out-of-pocket costs for families and people living with cerebral palsy in Australia’**](#) published in the open-access journal of science PLOS in July 2023, surveyed 271 people with cerebral palsy and their families, two thirds were regarding children and young people. The vast majority (94%) of those surveyed reported out-of-pocket costs, expenses relating to their condition over and above government support, despite 85% of respondents receiving some form of disability funding. Over a third (36%) of respondents reported experiencing “high to overwhelming” levels of financial distress.

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Median out-of-pocket costs for people with cerebral palsy and their carers was \$4,460 per-year, but those with more complex cerebral palsy experienced far higher out-of-pocket costs compared to people with independent mobility. For those in classified levels III-V on the five-level Gross Motor Function Classification System (GMFCS – a rating of movement abilities of a person with cerebral palsy), median out of pocket costs jumped to \$10,990.

The most common areas for out of pocket spending each year were on health , transport and home modifications , though these costs varied significantly based on a person’s age and individual experience of cerebral palsy. People with more complex cerebral palsy had much higher expenses relating to assistive technology and transport, and a majority also reported they would spend more in these areas if they were able to afford it. These costs are all associated with their disability, and it would be expected that most of these (other than health) would be covered by the NDIS. Survey participants were extremely grateful for the NDIS, for some it had been a game changer. This research shows however that there is scope to improve. Some people claimed things through the NDIS while others said that they couldn’t afford them at all, or that they were an out of pocket expense. How we best support people/families to ensure everyone can equally access what they need from the scheme to enable to them to participate more fully in society is a high priority.

The research follows on from a 2018 report by [Deloitte Access Economics](#), commissioned on behalf of Ability First, Cerebral palsy Alliance and Cerebral palsy Australia, which found that the total cost of cerebral palsy in Australia was \$5.17 billion – or more than \$145,000 per-person with cerebral palsy. Significant costs included in that are lost productivity, costs of disability support services, efficiency losses and lost wellbeing. It did not include out of pocket expenses, hence this recent research which confirmed that the lifelong management of cerebral palsy can pose significant financial costs to families and the economy.

Both reports indicate that the economic impact of cerebral palsy can be significantly reduced – by intervening early, improving access to health and aged services, supporting preventions and cures, and investing in the capacity of people with cerebral palsy to enter the workforce. This will be achieved off the back of improvements in the economic participation of people with cerebral palsy (in this study, only 9% of adults with cerebral palsy that responded had full time work), together with lower health and support costs through the lifespan.

Whilst the NDIS has revolutionised the financial support available to people with disability and families, there are often additional hidden costs associated with disability. For example, NDIS funding does not cover health costs (e.g. medication, specialist appointments, hospitalisation), which are often increased for people with a disability. CPA supports the Ministers public comments around this sector contributing more here so the NDIS is not the only lifeboat in the ocean.

Access to assistive technology (and trialling assistive technology) for children and adolescents with severe CP is imperative, providing the basic human right to mobilise, communicate and participate at home, school and within the community. CPA fully supports an increase in disability technology, particularly in solutions around transport and home modifications, as pioneered through our tech accelerator, [Remarkable](#).

A focus on reducing the severity of this condition, or reducing its prevalence, would make a material difference for our economy and in the day to day lives of people with cerebral palsy and their families. This



focus on early intervention for Australia's most common childhood physical disability would further reduce pressure on the scheme and on families out of pocket expenses by saving costs later as severity is reduced, leading to more economic participation of individuals and their families.

Thank you for the opportunity to submit a short, targeted response to the NDIS Review. At CPA, we are committed to working with you to improve the lives of people with cerebral palsy in Australia. Please reach out to Sarah McIntyre senior author on the paper and Theme Lead Epidemiology Research Institute on [REDACTED] for any further information.



Rob White
CEO, Cerebral palsy Alliance
25th August 2023