

**Submission
No 35**

IMPROVING ACCESS TO EARLY CHILDHOOD HEALTH AND DEVELOPMENT CHECKS

Organisation: Cerebral Palsy Alliance

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Improving access to early childhood health and development checks

Prepared by Cerebral Palsy Alliance

**For the Legislative Assembly Committee on
Community Services**

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To the Committee,

RE: Submission – Improving access to early childhood health and development checks

Dear Secretariat,

Cerebral Palsy Alliance (CPA) welcomes the opportunity to provide the Legislative Assembly Committee on Community Services' inquiry into improving access to early childhood health and development checks.

Over the last decade, Cerebral Palsy Alliance clinicians and researchers have partnered with NSW Health to have a huge positive impact in the space of early diagnosis and intervention for infants at risk of cerebral palsy. More than 400 infants and families have been supported by CPA Early Diagnosis Clinics, in the last five years, leading to increased and earlier access to therapies and interventions having a huge impact on the future for these families.

The insights from the work at the Early Diagnosis Clinic are particularly relevant to this inquiry, specifically in addressing Terms of Reference 4: "Funding for early intervention programs and screening to ensure children are given support for developmental issues."

Cerebral Palsy Alliance

An estimated 34,000 Australians have cerebral palsy (CP). It affects 1 in every 700 births and is caused by a brain injury during pregnancy or shortly after birth and is the most common physical disability in childhood. Cerebral Palsy Alliance (CPA) is committed to positively changing the lives of people with CP and similar 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 fulfil our vision for, and with, people with CP and their families – a global community of an estimated 17 million people.

Cerebral Palsy Alliance is a global leader in disability research through the CPA Research Institute, co-located at the University of Sydney's Brain and Mind Centre, which enables the world's foremost experts to explore prevention, treatment and cures for CP. Founded in 2005, the Research Institute is the world's largest dedicated CP research organisation, employing four of the top 10 experts in the field and published 150 landmark academic papers since 2020. It has significantly contributed to the drop in the prevalence of CP, which has seen a sustained decrease of around 40% from just twenty years ago, when one in 400 children were born with CP.

The CPA Research Foundation is the largest private funder of CP research globally, having provided more than \$67 million in grants to 714 projects across 154 academic institutes in 43 countries since 2005, with a specific focus on prevention, treatment and early diagnosis and detection.

CP early diagnosis and intervention

Despite the majority of CP being caused by a brain injury during pregnancy or shortly after birth, historically CP has not been diagnosed until between 12 and 24 months in high-income countries and even later in low- and middle-income countries.¹ Roughly 3% of NDIS participants have a primary diagnosis of CP,² making it the eighth most-common disability amongst scheme participants.

CP is a lifelong condition with no cure. However, the right, CP-specific evidence-based therapies and interventions provided at the right time can improve a person's wellbeing, quality of life and functional capacities. Early intervention, delivered in the first two years of an infant's life, is proven to give children the best chance of overcoming developmental disabilities.³

In 2014, Cerebral Palsy Alliance convened a summit of 40 leading cerebral palsy experts in Vienna with the purpose of plotting a future path towards early diagnosis. Three years later, international clinical guidelines for the early diagnosis of cerebral palsy were published by a team led by Cerebral Palsy Alliance researchers, establishing a gold standard for medical professionals.

¹ te Velde, A.; Morgan, C.; Novak, I.; Tantsis, E.; Badawi, N. Early Diagnosis and Classification of Cerebral Palsy: An Historical Perspective and Barriers to an Early Diagnosis. *J. Clin. Med.* (2019), 8, 1599. <https://doi.org/10.3390/jcm8101599>

² Annual NDIS dashboard: Participants with cerebral palsy (2023). Accessed via <https://data.ndis.gov.au/reports-and-analyses/participant-dashboards/cerebral-palsy>

³ Novak I, Morgan C, Adde L, et al. Early, Accurate Diagnosis and Early Intervention in Cerebral Palsy: Advances in Diagnosis and Treatment. *JAMA Pediatr.* (2017);171(9):897–907. doi:10.1001/jamapediatrics.2017.1689

The detection of CP requires a specific assessment approach including magnetic resonance imaging (MRI) combined with two other tests – the General Movement Assessment (GMA) and the Hammersmith Infant Neurological Examination (HINE). In particular, the GMA requires a high degree of training and skill, with clinicians assessing the spontaneous movements of infants in the first few months of life to identify the presence and quality of spontaneous movements that are highly predictive of CP.⁴

Since the launch of the clinical guidelines in 2017, Cerebral Palsy Alliance has funded and provided GMA training for clinicians and maternal health professionals in every Neonatal Intensive Care Unit (NICU) and Special Care Nursery in NSW and the ACT, as well as many other institutions across Australia and internationally – over 1,000 individuals. Around 10% of all babies born will spend time in a NICU - and 50% of babies with CP⁵ – and Cerebral Palsy Alliance’s close relationship with these NICUs is vital to the work of both early diagnosis and early intervention. We are fortunate enough to work hand-in-glove with the Grace Centre for Newborn Intensive Care (NICU) at the Children’s Hospital at Westmead, at the Sydney Children’s Hospital Network. The Grace Centre was awarded the prestigious NSW Health Research Award in 2023, in-part due to the impact of its partnership with Cerebral Palsy Alliance and a joint commitment to research excellence.

Follow up assessments for high-risk infants including those who have undergone major cardiac surgery, are growth restricted, have undergone major surgery or are preterm between 29- and 36-weeks’ gestation are patchy, only short term and are often funded by donations from the community. Babies from regional or rural areas or those from Aboriginal and Torres Strait Islander families, non-English speaking families or from lower socioeconomic groups are particularly disadvantaged and are slipping through the cracks despite them having the most to gain from follow up developmental programs.

“Every child deserves to have that chance in those very early weeks and months - not twelve months, not 18 months or two years as in some cases. The earlier the better to make sure that our kids aren’t falling through the cracks.”

- Parent of a Cerebral Palsy Alliance client

⁴ Morgan, C., Fetters, L., Adde, L., Badawi, N., Bancale, A., Boyd, R. N., Chorna, O., Cioni, G., Damiano, D. L., Darrah, J., de Vries, L. S., Dusing, S., Einspieler, C., Eliasson, A. C., Ferriero, D., Fehlings, D., Forssberg, H., Gordon, A. M., Greaves, S., Guzzetta, A., ... Novak, I. Early Intervention for Children Aged 0 to 2 Years With or at High Risk of Cerebral Palsy: International Clinical Practice Guideline Based on Systematic Reviews. *JAMA Pediatr*, (2021) 175(8), 846–858. <https://doi.org/10.1001/jamapediatrics.2021.0878>

⁵ Badawi, N., Novak, I., Morgan, C., Crowle, C. Early detection of cerebral palsy using general movements assessment and MRIs – a sensible way forward. *Pediatr Res* (2024). <https://doi.org/10.1038/s41390-023-03008-z>

Cerebral Palsy Alliance Early Diagnosis Clinics

Following the international clinical guidelines, Cerebral Palsy Alliance resolved to implement the suggested approach through the development of Early Diagnosis Clinics (EDC). Following extensive research on the ideal location and set-up, the first EDC opened in 2018 at Cerebral Palsy Alliance's Prairiewood therapy centre – the location in Western Sydney was deliberately chosen due to its fast-growing population and relative level of disadvantage, as there is a well-established socioeconomic gradient associated with disability.⁶

The multidisciplinary team at the EDC consists of a paediatric neurologist, a team of allied health professionals (occupational therapist, physiotherapist, and speech pathologist), plus a social worker and administrative staff such as an intake officer.

Families can be referred to the EDC via paediatricians, neonatologists, external therapists, GPs, or parents. Paediatricians and neonatologists are the largest referring groups (38%) followed by therapists in Cerebral Palsy Alliance's network (17%). Infants who meet the eligibility criteria are booked for an initial consultation, lasting up to two hours with the entire multidisciplinary team. Infants who receive a diagnosis of CP or at risk of CP are followed up in the clinic at multiple time points up to two years of age. Each appointment involves a comprehensive assessment including physical (including vision and pain), neurological, motor function, feeding, communication and parent well-being. Assessment results are fed back to families at each appointment and clear action plan is developed and shared with relevant professional who are involved in the infant's care.

Following the success of the first EDC, a second clinic was launched in 2021 at the Sydney Children's Hospital in Randwick. The third EDC, and the first in a regional location, opened in early 2023 at Croudace Bay, south of Newcastle. Operated in partnership with the Hunter New England Local Health District, it serves the Hunter and northern NSW regions.

Over the last five years, more than 400 infants and families have been supported across the three EDCs, which has featured in numerous academic and medical journals as a gold-standard model for CP diagnosis. Infants fall in to three general categories:

1. A baby with clear signs of CP and strong diagnostic evidence of brain injury may be diagnosed during the first consultation, connected to support services, and offered a referral to Cerebral Palsy Alliance or another evidence-based early intervention provider.

⁶ Solaski, M.; Majnemer, A.; Oskoui, M. Contribution of socio-economic status on the prevalence of cerebral palsy: A systematic search and review. *Dev. Med. Child. Neurol* (2014), 56, 1043–1051

2. A baby that definitely doesn't meet the criteria for CP diagnosis but may require ongoing follow up and/or further testing will typically be referred on to another specialist professional such as a paediatrician.
3. A baby may remain at risk of CP, taking multiple visits to confirm a diagnosis or rule out CP. Infants in the 'at risk' category immediately begin early intervention therapy regardless of their diagnosis.

After three years of EDC operations, a major academic study of the clinic found that infants with a high risk of CP were identified at an average age of 4.4 months of age, early intervention started at 4.7 months of age, and a formal diagnosis of CP was made at 8.5 months on average.⁷

The opening of the first EDC coincided with the Legislative Assembly's Committee on Community Services report into 'Support for new parents and babies in New South Wales'⁸, which noted that "children with disability aren't getting the early intervention that is critical to better long-term outcomes." The urgent need to improve the early detection of disability and improve timely support was noted in the report, with Recommendation 24 outlining that the "NSW Government reviews services for babies and children with developmental delay and disability, to address gaps and improve referrals for support."

Crucially, in attempting to address this gap for families the EDC doesn't just benefit children who go on to receive a formal diagnosis of CP. Of the 295 infants seen at Prairiewood from 2018 to July 2023, 57% were identified as having CP or a high risk of CP. The remaining 43% were either supported by Cerebral Palsy Alliance early intervention programs before a formal diagnosis was confirmed or referred on to relevant NSW Health services as available.

Ensuring this continuity of service ensures that there is no delay to crucial interventions prior to families receiving support from the NDIS or other sources, regardless of whether the infant has CP or a different neurological condition.

⁷ Te Velde A, Tantsis E, Novak I, Badawi N, Berry J, Golland P, Korkalainen J, McMurdo R, Shehata R, Morgan C. Age of Diagnosis, Fidelity and Acceptability of an Early Diagnosis Clinic for Cerebral Palsy: A Single Site Implementation Study. *Brain Sci* (2021). Aug 16;11(8):1074. doi: 10.3390/brainsci11081074.

⁸ Support for new parents and babies in New South Wales / Legislative Assembly, Committee on Community Services [Sydney, NSW.]: the Committee (2018) (Report no. 2/56 Committee on Community Services). Accessed via <https://www.parliament.nsw.gov.au/committees/inquiries/Pages/inquiry-details.aspx?pk=2461>

The wellbeing and support of families is also a major consideration for Cerebral Palsy Alliance in operating the clinics. A diagnosis of CP can be a huge shock to a family with a young baby. The provision of structured support through a social worker, who is trained and equipped to deliver supportive and respectful care, ensures families receive timely resources and supports following diagnosis.

“I had a gut feeling early that there was something not quite right. We were told all along that we just had to wait and see. For nine months, my husband and I spent our time not being able to enjoy our baby because we were trying to seek out answers. It was such a wasted time because that window of opportunity was lost.”

- Parent of a child with CP who didn't receive early intervention

The cost of running the EDC is high, given the intensive nature of the service, with multiple medical experts and visits – each individual appointment costs roughly \$3,000 in staffing costs, and with four appointments each day across three sites, Cerebral Palsy Alliance invests significant funds into the EDC. While some support has been gratefully received from the state government and family visits can be covered by Medicare, the vast majority of the EDC's operating cost has been borne by the organisation's fundraising through corporate partners, grants, charitable foundations and donors.

Cerebral Palsy Alliance justifies this cost through the EDC's close connection to our mission – to champion a world of opportunity for people living with CP and similar disabilities, and their families. There is also a robust economic argument for early intervention – a 2018 Deloitte Access Economics study has found that the total cost of CP in Australia, after calculating lost productivity, disability support services and efficiency losses was \$5.17 billion, or \$145,642 per-person with CP.⁹ In the long-term, better outcomes for children who receive an early diagnosis will mean less resources to support them over the lifespan.

For many infants diagnosed through EDCs, Cerebral Palsy Alliance also provided CP-specific therapy intervention until families were accepted for a NDIS plan – a lag of weeks or months in many cases. In the last financial year to 30 June 2023, some 3,740 hours of therapy was provided free of charge to 233 infants through the 'Babies at Risk' program.

⁹ The cost of cerebral palsy in Australia in 2018 / Deloitte Access Economics prepared for Cerebral Palsy Australia, Cerebral Palsy Alliance, and The Australasian Academy of Cerebral Palsy and Developmental Medicine (2018). Accessed via <https://cerebralpalsystrategy.com.au/resources/>

Early Childhood Approach partnership

Between 2018 and 2023, Cerebral Palsy Alliance was the official Early Childhood partner (formerly known as Early Childhood Early Intervention) in Northern Sydney for the NDIS. In this capacity, the organisation supported families to navigate the NDIS, understand funding, develop plans and provide guidance on services that will best meet the needs of children aged between 0-6. During this time, more than 2,500 children and families, completing 2,100 first plans and 1,900 plan reassessments.

Roughly 30 staff operated out of Cerebral Palsy Alliance Allambie Heights and Ryde therapy centres were involved in the program, including a highly-trained team of Early Childhood Coordinators – a role which involves meeting with families, obtaining all clinical and diagnostic information on a child and identifying the support required. While not required by the NDIS, Cerebral Palsy Alliance resolved early in the Early Childhood partnership that in order to best support families, the Coordinator role would need to be staffed by experienced clinicians from an allied health background with training in tailored, research-led interventions.

Other staff included a team of occupational therapists, speech pathologists, psychologists and physiotherapists, alongside social workers and early childhood educators and administrators, to provide the highest possible standards of care to families. Our service provision was commended by the NDIS for the professional, high-quality services we provided and the collaborative relationship we developed with the Agency. Over five years we delivered more than 100 workshops on a wide range of topics for caregivers, families, and service providers, as well as thousands of 1-on-1 support sessions across northern Sydney.

Cerebral Palsy Alliance's approach to the Early Childhood partnership was to invest in qualified allied health staff to provide the best possible support to families. Trained clinicians with specialist knowledge of paediatric disabilities were able to refer families to trusted, evidence-based services for further support for conditions such as developmental delay, autism, and physical disability.

“CPA's Early Childhood program is absolutely instrumental and we're seeing continuous improvements which we never thought would achieve. We express all our gratitude to the amazing program. It's giving my child and family a chance in life.”

- Parent of a Cerebral Palsy Alliance Early Childhood client

Rural and remote services

Cerebral Palsy Alliance operates sixteen therapy centres across NSW and the ACT. This network ranges from large, purpose-built facilities in metro Sydney to small, regional outposts in towns such as Alstonville, Dubbo, and Orange.

This state-wide footprint enables Cerebral Palsy Alliance to observe the increased vulnerability of children in regional settings. Across the entire therapy network, the average age of referral is around seven months of age, whereas in Alstonville in the northern rivers region it is 16 months, indicating that access to early childhood health and development is difficult in regional locations. The 2023 Australian CP Register Report¹⁰, a major epidemiological study including data from nearly 11,000 people, indicates that 30% of Australians with CP live in regional, rural, or remote settings. This is a higher rate than the overall population, indicating the need for high quality, accessible and culturally safe health services.

In response to the COVID-19 pandemic, Cerebral Palsy Alliance also invested significant time and effort in expanding telepractice and making it more accessible – over the last two years, almost 29,000 hours of therapy services have been delivered via telepractice.

Due to financial constraints of offering services to remote areas and difficulties in attracting therapists to these areas, Cerebral Palsy Alliance has also had to re-design programs and supports to service communities by launching ‘fly-in-fly-out’ (FIFO) therapy services in the Central West of NSW. A team of three allied health experts – occupational therapist, physiotherapist, and speech pathologist – provide regular support to young children whose complex disabilities make travel to regional centres difficult, again demonstrating these difficulties in access.

“My [daughter] had screening done within the first few days of her life and that has set us on the path. I really do think that the early start has meant the world... As far as I'm concerned, early screening has set her up for a life that she should have.”

- Parent of a Cerebral Palsy Alliance client

¹⁰ Australian Cerebral Palsy Register. Report of the Australian Cerebral Palsy Register, Birth years 1995–2016. (Cerebral Palsy Alliance Research Institute, Sydney, 2023). Accessed via: <https://cerebralpalsy.org.au/research/research-projects-priorities/cp-register/>

Summary and recommendations

Despite being the most common physical disability in childhood, there is no universal early screening program for cerebral palsy in Australian hospitals, with varying levels of screening occurring across different health networks to detect the condition. Some babies considered at high risk of cerebral palsy (typically those born extremely pre-term who spend time in neonatal intensive care units) are screened, however pre-term births account for just less than half of infants with cerebral palsy.

For families who aren't channeled through the Early Diagnosis Clinics or similar pathways, diagnosis comes much later – often too late for early intervention therapy to have the best impact. A late diagnosis doesn't just affect the development of the infant, but also leads to significant stress and anxiety for families who often spend this vital period seeking medical diagnoses without formal disability support.¹¹

Following significant success in piloting and operating three Early Diagnosis Clinics, Cerebral Palsy Alliance is now actively exploring new models to reach more children and families. A long-term organizational vision is to roll out a universal national early screening program in all newborns to detect CP at three months of age using the General Movements Assessment, with its extremely high accuracy (above 95%)¹² making it the most impactful diagnostic test.

“The best part of my day is helping anxious parents get answers and a pathway forward for their baby and family. I often hear from families once they are referred on to CPA that their initial experience at the Early Diagnosis Clinic was a catalyst to their acceptance and peace of mind that they would get the best outcome for their child. It feels wonderful to be a small part of that outcome.”

- CPA Early Diagnosis Clinic staff member

The Early Diagnosis Clinic has engaged with an estimated 19% of children with CP in NSW born since the launch of the first clinic – this high proportion indicates the enormous opportunity to reach the majority of infants in the state with a better-resourced, up-scaled early diagnosis model which could further decrease the age of diagnosis and position NSW as a global leader in diagnosis.

¹¹ Follow Your Instincts: Parent insights on having a child with disability – 4th edition revised (Cerebral Palsy Alliance, Sydney, 2020). Accessed via: <https://cerebralpalsy.org.au/services/early-childhood-intervention/>

¹² Goyen, T. A., Morgan, C., Crowle, C., Hardman, C., Day, R., Novak, I., & Badawi, N. Sensitivity and specificity of general movements assessment for detecting cerebral palsy in an Australian context: 2-year outcomes. *Journal of paediatrics and child health*, (2020) 56(9), 1414–1418. <https://doi.org/10.1111/jpc.14953>

Commencing CP-specific early interventions in the first few months of life is likely to be key to decreasing the severity of impairments, as neuroplasticity is enhanced in the young brain. But despite the successes in early diagnosis and intervention, 75% of babies with CP are not diagnosed until after six months of age, missing this window of peak neurodevelopment when interventions can have the greatest impact toward reducing the severity of disability.

Combined with the geographically constrained footprint of the EDCs, the high operating cost of the clinics is an ongoing risk to the future sustainability of the program. Cerebral Palsy Alliance recommends that NSW Health expands other early screening tools to include CP and firm up pathways to early therapy and intervention.

Cerebral Palsy Alliance is currently plugging a vital gap in the state health infrastructure and has demonstrated that early diagnosis and intervention of CP is achievable, viable and leads to positive outcomes for families and a brighter future for young people with disabilities. Our recommendations are as follows:

- **Recommendation 1:** Early diagnosis and detection of CP is considered a priority as a way of reducing the life-long impact of disability, and the NSW Government explores the viability of including early screening of CP alongside the suite of other early childhood checks currently conducted as standard care.
- **Recommendation 2:** Funding is made available to enable the ongoing delivery and expansion of Early Diagnosis Clinics and recognise the important role they play in supporting infants at risk of CP and their families.

We thank the committee for providing us the opportunity to share our insights in the early diagnosis and detection space and would welcome the opportunity to provide further details at an inquiry hearing.

Regards,

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