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**POSITION PAPER**

# Developing a Foundational Supports Strategy and Service System for Children with Developmental Concerns, Delays, or Disabilities

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Cerebral Palsy ALLIANCE

Cerebral Palsy AUSTRALIA

Disability Assembly WA
A collective voice for people with disability

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## Purpose of this paper

The purpose of this paper is to inform the work of governments to define the National Foundational Supports Strategy and to suggest essential service design and delivery for children under nine years of age at risk of complex disabilities such as cerebral palsy (CP).

## Who we are

We are an alliance of service providers, peak bodies, researchers and health organisations who collaborate on the ANZ CP Strategy to drive research and advocacy for people with CP across Australia. Each organisation holds deep expertise in all aspects of cerebral palsy.

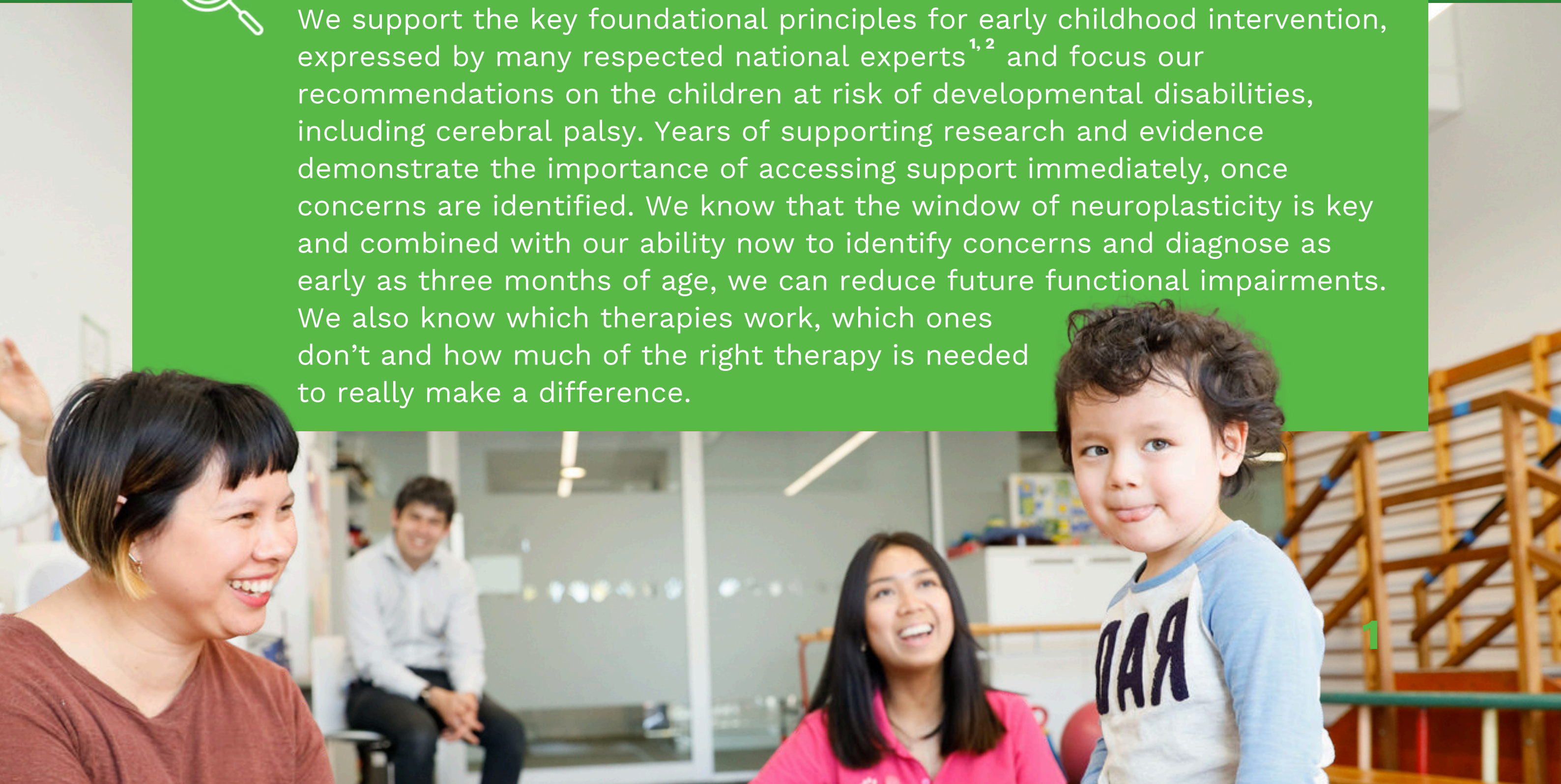
## The current state of early childhood supports

The supports provided to young children with developmental concerns through the National Disability Insurance Scheme have become increasingly fragmented for families, leading to stress and confusion. Most concerningly, the outcomes intended by the scheme – for children to receive early, proportionate, evidence-based care and support - are not being met. Delivering these services successfully is crucial to enabling children to reach their developmental potential, transition to school successfully, be less reliant on specialist NDIS support and participate fully and independently in their communities.

Given that the trajectory of children with developmental concerns cannot be fully assessed for some time, funding should be provided while assessments are made across children's developmental milestones and health professionals are monitoring across domains.

## Our commitment to research and best practice

We support the key foundational principles for early childhood intervention, expressed by many respected national experts[1,2] and focus our recommendations on the children at risk of developmental disabilities, including cerebral palsy. Years of supporting research and evidence demonstrate the importance of accessing support immediately, once concerns are identified. We know that the window of neuroplasticity is key and combined with our ability now to identify concerns and diagnose as early as three months of age, we can reduce future functional impairments. We also know which therapies work, which ones don't and how much of the right therapy is needed to really make a difference.



## Our commitment to children with CP and their families

There are around 34,000 people living with CP in Australia, with approximately 1 in 700 babies born with CP each year. CP is the primary diagnosis of 3% of NDIS participants, with an average annualised NDIS spend of $142,000 per-person.[3]

The complexity of this condition cannot be understated: in a landmark study, among children with CP - 3 in 4 were in pain; 1 in 2 had an intellectual disability; 1 in 3 could not walk; 1 in 3 had a hip displacement; 1 in 4 could not talk; 1 in 4 had epilepsy; 1 in 4 had a behaviour disorder; 1 in 4 had bladder control problems; 1 in 5 had a sleep disorder; 1 in 5 dribbled; 1 in 10 were blind; 1 in 15 were tube-fed; and 1 in 25 were deaf.[4]

More recent studies are also acknowledging the comorbidity between cerebral palsy, autism spectrum disorders and ADHD,[5] highlighting that a spectrum of neurodevelopmental concerns likely exists and should not be considered in isolation of each other.[6]

Despite advances in the sector supporting this low prevalence yet high impact complex condition, there is limited community understanding and awareness and no single source of truth for participants, professionals and governments to support their referral and capacity building needs.

We believe that if the right mix of specialist supports are made available for children with CP/high risk of CP, in alignment with international best practice guidelines[7]– most children are likely to achieve sufficient developmental progress to transition successfully to mainstream health and education agencies by age 9 for most of their ongoing care.[8]

## PROPOSED SOLUTIONS

Given our deep expertise, our solutions are focused on the management of complex conditions such as cerebral palsy, but these solutions will benefit other children with emerging complex physical/neurodevelopmental disabilities.

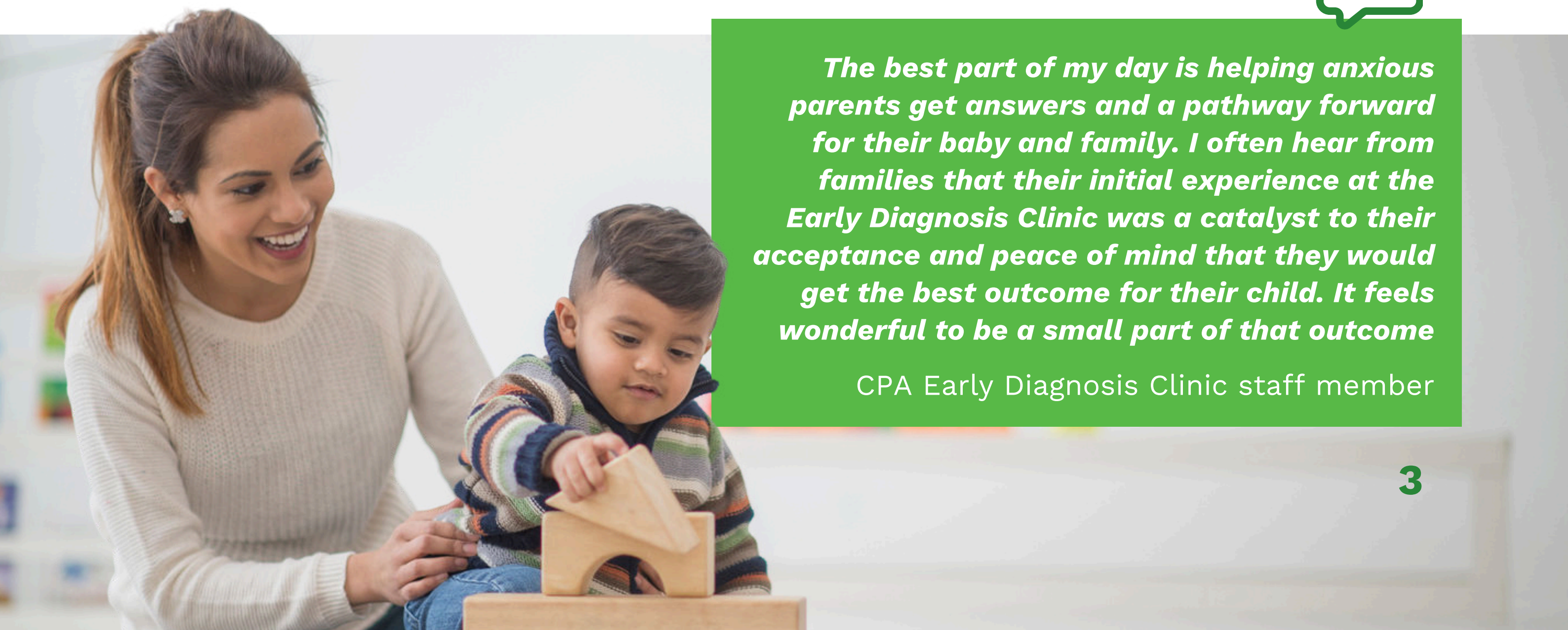
### Mainstream Supports (Tier 1)

As we know, there is a strong need to improve early detection, diagnosis and support for young children. With a major focus on children with ASD/ADHD, children with CP and similar complex conditions are often going undetected, misdiagnosed or needing to wait unacceptable timeframes to get sub-optimal packages of support as the support system relies on evidence of functional impairment rather than evidence of risk factors. There are also children with no detectable risks and seemingly healthy at birth, but risks emerge that are less likely to be followed up or followed up very late.

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.[9] Early diagnosis also allows for timely psychological support for parents. We know most parents suspect CP before receiving a diagnosis and that they found early diagnosis beneficial.

**Solution:**

1. **Establish a network of early detection clinics in every capital city for children to detect physical/neurodevelopmental disabilities earlier**
    - This will lead to increased and earlier access to specialist early intervention supports and to increase the role of allied health and nursing professionals, ultimately reducing the lifetime impacts of the disability and overall future costs to governments.
    - Early detection clinics would work with state-based screening/detection activities within Health systems and link to child/family services and early learning and care settings, strengthening a more integrated service system.
    - Cerebral Palsy Alliance has piloted 3 Early Detection Clinics in NSW, and would welcome the opportunity to work with governments to share learnings and the design of this successful service model.



> ***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 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

## General and Targeted Foundational Supports (Tier 2)

The NDIS is not family friendly, with families neglected due to the individualised nature of the scheme. For children with identified emerging or low support needs, we put forward that families need information & advice and individual & family capacity building to guide and support them at the initial stages of diagnosis and guide referrals. Referrals to social supports are essential for families. We also know improved training and capacity-building for allied health professionals is essential for getting Foundational Supports right.

**Solutions:**

**2. Information for families**

- Continue My CP Guide as a one stop shop for families and clinicians through an online portal (currently funded under ILC, led by CP Australia)
- Roll out the mHealth app, a mobile health aide that streamlines and filters evidence-based intervention options (part of TRANSMIT study focusing on narrowing the research-practice gap using evidence-based multifaceted knowledge translation strategies. NDIA is a funding partner).

**3. Improved training and capacity building for allied health professionals**

- Deliver capacity building supports to allied health professionals nationally via a comprehensive evidence-informed online postgraduate training package, currently being developed by CPA and in line with the CP clinical guidelines.[8] This ensures a consistent approach, given the limited focus in undergraduate and postgraduate medical and allied health programs on CP, to ensure best practice approaches are used wherever children live or who they are supported by.

> ***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

## Specialist Supports (Tier 3)

For children with high support needs and/or lifelong conditions who require specialist services, starting early is the key to decreasing the severity of impairments, as neuroplasticity is enhanced in the young brain.

As the most common physical disability of childhood, the 5th most common cause of childhood death, and Australia's 5th most expensive healthcare condition, CP is lifelong with no known cure. People are not able to access effective treatments (43% do not receive known effective interventions,[10] and 20% receive harmful or ineffective care); resulting in lost opportunity that decreases the likelihood of long-term independent living and employment, the chief object of the NDIS.

Children need access to specialised care clinics and highly trained and supported allied health professionals until the level of future need is assessed and/or at risk of a CP diagnosis. For many, the interventions these young children need are not provided by generalist community-based providers.

For the cohort of children with emerging physical/neurodevelopmental conditions, specialised and evidence-informed best practice early supports are required until their needs can be adequately assessed. Deciding eligibility for NDIS supports on the basis of the GMFCS[11] level alone (i.e. motor function) is limiting and leads to a significant proportion of children with milder CP being ineligible for funding or receiving inadequate interventions short term. Age is an important consideration, especially for children under 24 months of age, given the limitations using functional assessments only as they cannot demonstrate delays in one or more areas – therefore a diagnostic risk profile is required.

**Solutions:**

**4. All children with CP receive individualised specialist services until at least 8 years of age, regardless of functional severity.**
**5. A centralised centre for research (CRC) collaboration for clinicians to access the most up to date research and evidence to inform their practice**

- Accelerating practical research and evidence informed intervention guidelines that can benefit all Australians with CP through a nationally coordinated centre would be of immense benefit. Bringing together research, funding and support across the sector, universities, hospitals and clinics around the country, a CRC would encapsulate and translate research and policy recommendations for young children with physical/ neurodevelopmental disabilities.

## IN CONCLUSION

Overall, our position is that all children with CP need access to early intervention as soon as possible, ideally diagnosing at 3–6 months of age, but certainly within the optimal window of neuroplasticity up to 24 months, with further appropriate and evidence-based interventions being delivered until 9 years old.

A nationally consistent approach to developmental monitoring and screening will ensure children with developmental concerns, including complex disability, will be identified earlier, giving them access to the right mix of supports and services in childhood. Unfortunately, more than 75% of babies with CP are not diagnosed until after 6 months of age, missing this window of peak neurodevelopment when interventions can have the greatest impact toward reducing the severity of disability.

## SUMMARY OF RECOMMENDATIONS

- ✓ Establish a network of early detection clinics in every capital city for children to detect physical/neurodevelopmental disabilities earlier.
- ✓ Continue My CP Guide as a one stop shop for families and clinicians through an online portal and roll out the mHealth app, a mobile health aide that streamlines and filters evidence-based intervention options.
- ✓ Deliver capacity building supports to allied health professionals nationally via a comprehensive evidence-informed online postgraduate training package.
- ✓ Continue individualised specialist services until at least 8 years of age, regardless of functional severity.
- ✓ A centralised centre for research collaboration for clinicians to access the most up to date research and evidence to inform their practice.

## SUPPORTING ORGANISATIONS

This document has been developed by Cerebral Palsy Alliance in partnership with a coalition of leading disability service providers and peak industry bodies, each with an established track record of excellence in supporting young people with disabilities through early intervention programs. The below organisations, representing tens of thousands of people with disabilities and their families, are co-signatories and endorsing partners of this paper:

ability first AUSTRALIA

Cerebral Palsy ALLIANCE

Cerebral Palsy AUSTRALIA

Disability Assembly WA
A collective voice for people with disability

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