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APRAXIA NDIS SUPPORT & ADVOCACY

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APRAXIA THERAPY

Apraxia NDIS Support & Advocacy Group – Position Statement on the National Disability Insurance Scheme June 2025

Our Goal

This position statement has been developed by Australian speech pathologists, families, and advocates working together to improve outcomes for children with Childhood Apraxia of Speech (CAS) through a practical and evidence-informed approach. Our group is focused on ensuring families can access the intensive, specialist support their children need to live fully, without unnecessary barriers or disruptions to care.

Background Information about CAS:

CAS is a rare, lifelong, neurological, and permanent speech disorder. Childhood Apraxia of Speech is recognised in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), under the category of Verbal Apraxia. This formal classification highlights its status as a neurodevelopmental speech disorder requiring clinical recognition and tailored support.

Researchers worldwide, including those at universities and the Murdoch Children's Research Institute (MCRI), are actively investigating the causes of CAS. MCRI's research has revealed at least 1 in 3 children with CAS have a genetic variation responsible. **CAS affects 1-2 in 1000. This prevalence is similar to that of Down Syndrome**, yet CAS remains poorly understood and often overlooked by the community and government services. CAS significantly impacts a person's functioning in daily life. It is not to be mistaken as a speech delay or disorder that children can grow out of and that only impacts speech. CAS research has influenced the evidence-based assessment and treatments in recent years. **Without intensive intervention, children with CAS do not experience significant speech improvement.** The research highlights 3-4x weekly is needed and while treating apraxia can become less tractable as children age, speech pathologists who are trained to provide evidence-base treatments to those with CAS continue to see improvements beyond the early years. This means, removing a child's eligibility at the age of nine is not in line with the evidence and does not support a child in the long term.

The NDIS has the potential to give children and teenagers with childhood apraxia of speech the support they need with more choice and control and less anxiety and red tape. The lives of so many children and teenagers currently on the NDIS with CAS have been significantly improved already. However, there have been lots of inconsistencies with NDIS funding and approvals which is causing high anxiety, frustration, and potential harm to people with CAS and their families.

Broader Impacts of CAS on Development and Daily Functioning:

Untreated or inadequately treated Childhood Apraxia of Speech (CAS) can have serious long-term consequences beyond speech alone. These include:

- **Social communication difficulties**: Children with CAS often struggle to initiate and sustain interactions with peers, leading to social isolation and reduced confidence in group settings (Lewis et al., 2011).
- **Academic underachievement**: Persistent speech and language difficulties can impact early literacy, reading fluency, spelling, and written expression, affecting performance across subjects (Lewis et al., 2004; Ruben, 2002).
- **Mental health**: Longitudinal studies have linked CAS to higher rates of anxiety and depression in adolescence and adulthood (Carrigg et al., 2016; McCabe et al., 2017).
- **Functional participation**: Many children with CAS experience challenges with daily communication routines, such as asking for help, expressing emotions, or participating in community settings — all of which impact independence and quality of life.

These impacts cross multiple domains considered under Sections 24 and 25 of the NDIS Act, including communication, learning, social interaction, and self-management.

The impact of excluding supports for children with CAS:

Removing specialist speech pathology intervention for CAS would result in people with CAS facing **continued challenges and further impacts on their social, emotional, and psychological wellbeing.** These may include **mental health difficulties**, **reduced confidence communicating** in everyday settings such as ordering food in a restaurant or making a phone call, and significant **barriers in education and future employment.**

Where things stand for families with CAS:

- **Plans taking over 12 months from the initial contact with the Early Childhood Partner or Local Area Coordinator**
- **Inconsistency in approvals**
- **Inconsistency in funding**
- **Too many steps and forms to fill out creating barriers for families, particularly our vulnerable community, in accessing NDIS**
- **Too many workers within the NDIS not understanding CAS and telling parents it is like another speech delay or disorder**
- **Variability in NDIS worker skills right through the NDIS and provider workforce.**

- **High anxiety for parents of children and teens with CAS around their child's funding and risk of losing funding.**

Our Key Priorities

• 1. Recognise the Lifelong Impact of CAS:
Childhood Apraxia of Speech should not be grouped with other speech and language delays under generalised early intervention criteria. CAS is a neurological disorder that is lifelong, impacting children beyond their early years, requiring a long-term, tailored approach. Children with CAS need early, intensive therapy and — crucially — ongoing access to support into their school years and adolescence.

• 2. Protect Family Choice:
The process of mandatory NDIS provider registration for small providers must be reconsidered and the voices of small business owners heard and considered. Mandatory NDIS provider registration risks disrupting established therapeutic relationships. Families must be able to continue working with their trusted, qualified speech pathologists — many of whom are small providers with specialist experience in CAS.

• 3. Oppose Arbitrary Age Cut-offs:
We strongly oppose the NDIS's arbitrary age-based cut-off for support, which often removes or limits funding at the age of 7 — if families are lucky enough to have received support by then. This policy fails to reflect the lifelong impacts of CAS and leaves children without essential services during key stages of development. Support should be based on functional need, not age. There are many upper primary school aged children and teenagers living with apraxia who have had limited to no intervention due to difficulties accessing funding support to access services.

• 4. Fund Early Intensive Support:
We advocate for increased NDIS funding during the severe stage of CAS, when the need for high-frequency, specialist therapy is greatest. A minimum of twice weekly, with the best outcomes when therapy is delivered 3–4x per week in blocks of therapy having the best outcomes. Early investment can prevent long-term consequences and reduce the overall cost to the government long term. Adolescents for example are already expressing social anxiety and have limited their own employment options due to the need to communicate verbally in many jobs.

• 5. Reject the Foundational Supports Model for Severe CAS:
We oppose placing children with severe CAS into the upcoming "Foundational Supports" service delivery model, which is scheduled to roll out in 2025. This model, designed for lower-level and short-term support, is NOT appropriate or effective for children with complex, persistent speech motor planning needs like those with CAS. These children require frequent, individualised, and highly specialised intervention that is ONLY evidence based when delivered by trained speech pathologists.

• 6. Address Access Gaps and Inadequate Alternatives:
More and more children with confirmed CAS are being denied access to the NDIS, despite having clear functional impacts and limitations. For families ineligible for the NDIS, the current alternative — 5 Medicare-funded sessions per year under the Chronic Disease Management Plan and hopefully up to 20

Medicare-funded sessions once in a person’s lifetime if they are involved with a paediatrician or psychiatrist — falls drastically short of what is needed. These limits are inconsistent with best-practice recommendations and will leave children at risk of poor long-term outcomes.

• 7. Reject Inappropriate Functional Assessment Requirements for CAS:
We are concerned that the proposed NDIS "needs assessments" may not be adequately tailored to capture the unique challenges of Childhood Apraxia of Speech (CAS). Standardised tools and assessments conducted by generalist practitioners, including NDIS-employed speech pathologists without specific CAS expertise, risk misrepresenting the needs of children with this complex disorder.

We oppose any NDIS requirement that compels families to substantiate their child's disability through assessments not designed for CAS. Instead, we advocate for the recognition of diagnoses and clinical evidence provided by qualified speech pathologists with demonstrated expertise in CAS, supported by goal-based outcomes and developmental trajectories. Ensuring that assessments are conducted by professionals with specific training in CAS is vital for accurate diagnosis and effective intervention planning.

• 8. Advocate for Recognition of Severe CAS within the NDIS Disability Framework
We advocate for severe CAS to be formally recognised as a disability within the NDIS eligibility framework, due to its complexity, permanence, and significant impact on functioning. The NDIS classification should reflect the condition's long-term implications for communication, social participation, education, and future employment.

Call to Action

We urge the NDIS Minister and government officials to:

- **Reconsider mandatory provider registration** to ensure families can continue working with their trusted therapists.
- **Recognise CAS as a lifelong disability** by updating policies to reflect ongoing support needs.
- **Remove arbitrary age limits for funding** and ensure decisions are based on need, not a child’s birthdate.
- **Increase funding for intensive therapy** during the severe stage to avoid long-term impacts and reduce the costs associated with delayed or inadequate treatment.
- **Exclude children with severe CAS from the foundational supports model** and instead provide access to individualised, high-frequency supports.
- **Ensure children with a confirmed CAS diagnosis are not excluded from accessing NDIS supports** and review current eligibility practices.

Supporting Evidence

- **Importantly**, Childhood Apraxia of Speech is recognised as a **primary disability** within the NDIA’s internal Standard Operating Procedure (SGP KP Publishing, FOI 24/25-0754). This document, released under Freedom of Information, outlines accepted disability categories for **planning and**

eligibility purposes. CAS is listed explicitly on page 86, providing **further justification** for access to early intervention funding.

- **On request, we will share compelling stories** — including that of three children who missed their critical therapy windows due to system delays — to demonstrate the urgent need for systemic reform. These are not isolated cases. They represent a widespread failure to meet the needs of one of the most vulnerable and under-recognised groups of children with disability in Australia.
- **Research shows that children who do not receive appropriate, intensive early intervention for CAS are at increased risk of experiencing long-term challenges.**
- **Apraxia evidence brief by the University of Sydney:** https://rest.sydney.edu.au/wp-content/uploads/2024/01/CAS_evidence_brief_2024.pdf
- **Childhood Apraxia of Speech genetics research (MCRI):** http://geneticsofspeech.org.au and factsheet https://www.geneticsofspeech.org.au/media/kdknhaot/cas_fact_sheet_07-06-23_translationalcentreforspeechdisorders_flyertemplate.pdf
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We stand ready to collaborate with the NDIS and government officials to ensure children with CAS receive the supports they deserve. Let's work together to create a system that meets their needs.

Please don't hesitate to contact the Apraxia NDIS Support and Advocacy Group on info@olgakomadinapraxiatherapy.com.au