

**Submission  
No 39**

**IMPROVING ACCESS TO EARLY CHILDHOOD HEALTH AND DEVELOPMENT  
CHECKS**

**Organisation:** Australian ADHD Professionals Association

**Date Received:** 29 February 2024

**Thursday, 29 February 2024**

To: Legislative Assembly Committee on Community Services  
C/ communityservices@parliament.nsw.gov.au

To the Committee

RE: Inquiry into improving access to early childhood health and development checks  
On behalf of the Australasian ADHD Professionals Association (AADPA) and the AADPA Research Committee, we would like to thank the Community Service Committee for the opportunity to make a submission to this inquiry.

AADPA is a national not-for-profit association representing healthcare professionals in Australia and New Zealand involved in the assessment, diagnosis, and support of ADHD. Our membership is broad and includes researchers and academics, psychiatrists, paediatricians, psychologists, general practitioners, nurses, many other allied health professionals, ADHD Coaches and people with lived experience.

Since 2019 AADPA Board has led the following national collaborative projects:

- Australian Evidence-Based Clinical Practice Guideline for ADHD (2022)
- Australian Evidence-Based Clinical Practice Guideline for ADHD: Consumer Companion Guide (2023)
- The Social and Economic Costs of ADHD (Deloitte Access Economics – 2019)
- National Prescribing Manual (In development)

In NSW, AADPA members have been instrumental in developing collaborative and innovative e-learning modules to assist clinicians in addressing issues identified in the Henry Review (2020) and will enable two ADHD trials in regional NSW.

Based on the evidence synthesised in the ADHD Clinical Practice Guideline, our own research, and our collective experience and expertise, our submission identifies barriers to improving access to early childhood health and development checks and suggests several solutions.

ADHD is the most common neurodevelopmental disorder for children in Australia and with extremely high rates of co-occurring conditions across all disability, we advocate for a developmental check framework that would allow for better education for health professionals to enable the identification of potential symptoms and referral to existing diagnostic pathways in LHDs.

Our recommendations complement and could be integrated with existing policies, reports, and initiatives. These includes the \$111m Health and Development Participation Grant Program (2023), the Henry Review (2020) and it also builds on the work of the NSW Mental Health Commission.

Critical to the success of future strategies aimed at improving access to development checks in NSW is the active involvement of families, frontline clinicians, and individuals with lived experience. This inclusive approach is particularly vital for First Nations and CALD communities to ensure the effectiveness of these strategies.

Please do not hesitate to contact me or any member of the Research Committee at [committees@aadpa.com.au](mailto:committees@aadpa.com.au)

Yours sincerely,

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**On behalf of the AADPA Research Committee.**

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## **Inquiry into improving access to early childhood health and development checks**

### **Background**

The early childhood health and development checks conducted by NSW Health for decades, play a crucial role in promoting the health and well-being of children in NSW. By identifying potential health or developmental concerns early on, these checks can help to ensure that children receive the support and interventions they need to thrive.

These checks are typically conducted by a range of healthcare professionals, including child and family health nurses, general practitioners (GPs), and paediatricians. They are designed to monitor children's growth, development, and overall health from birth to school age in six key domains:

- Physical growth;
- Developmental milestones;
- Hearing and vision;
- Immunisations;
- Nutrition and feeding;
- Parental support and education.

The NSW Government's 2023 Health and Development Participation Grant Program (HDPP), that aims to provide free health and development checks to 4-year-old children within early childhood education and care settings; as well as the 2024 introduction of the digital "Child Personal Health Record" or the "Blue Book", will hopefully increase access to developmental checks. However, there is widespread anecdotal evidence that critical workforce shortages will impact the full implementation of the HDPP program.

According to NSW Health data, 2 out of every 5 children are starting school without reaching all developmental milestones. Despite considerable delays between identifying developmental concerns and receiving a diagnostic assessment, empirical research suggests that around 1 in 7 children in Australia have a neurodevelopmental disorder (NDD), with similar rates likely in New South Wales.

Of these, Attention Deficit Hyperactivity Disorder (ADHD) is the most common. The prevalence of ADHD in children aged 0 to 14 years in Australia has been reported at 4.1%.

Attention deficit hyperactivity disorder (ADHD) is classified as a neurodevelopmental disorder with an onset typically before 12 years of age. Symptoms include difficulties with attention and/or hyperactivity and impulsivity, which are incongruent with a person's age and interfere with activities, including a person's family life or participation in their community.

Further, research has also shown that children with ADHD who did not receive early intervention were more likely to have academic problems, conduct problems, substance abuse problems later in life, and reduced quality of life. ADHD is associated with substantial social economic costs, with the disproportionated distribution of the cost burden on the more disadvantaged families. Empirical research shows that childhood health has strong long-term impacts on both socioeconomic position and health in adulthood. The importance of early childhood development for improving population health and reducing inequities has been widely recognised.

KEY POINTS:

- ❑ Over the last decade, there has been a substantial increase in ADHD diagnoses. This surge has significantly raised the workload of public paediatricians, with 50-70% of cases in their care involving ADHD. As identified in the Henry Review, this demand has overwhelmed outpatient services in hospitals and communities, surpassing their capacity. ADHD has become a dominant diagnosis in these clinics.
- ❑ AADPA highlights improved access to early childhood health and development checks as a crucial opportunity for enhancing ADHD-related service delivery. Timely diagnosis and intervention not only benefit individuals and families but also leads to positive outcomes in daily life and academic performance, ultimately improving overall quality of life.
- ❑ Current diagnostic practices often do not align with best practices, as outlined in guidelines from [AADPA](#) and [NICE](#) (National Institute for health and Care Excellence). Delays in diagnosis are common across services, and significant out-of-pocket costs are frequently linked to both diagnosis and treatment.
- ❑ The Henry Review highlighted a notable transition from private practice to public services as the preferred model for consultant paediatricians. This shift is exacerbated by the high cost of diagnosis within the private system. Implementing screening within early childhood health and development checks emerges as a pertinent strategy to integrate ADHD-related skills and support into the public system, including community health centres and GPs.
- ❑ The Henry Review also recognised the increasing demand for services and some variation in the management of ADHD and strongly recommended a review of the model of care for ADHD service delivery. Trials and models of care are still being developed.
- ❑ Primary care professionals should be better trained into recognise ADHD and other neurodevelopmental disorders, and enhanced triaging processes during developmental checks will help identify appropriate diagnostic and treatment pathways. This approach enables early diagnosis and timely access to services, minimising the lifelong economic, social, and health impacts of ADHD.
- ❑ Invest in the development of resources about developmental delays and neurodevelopmental conditions to provide to families. This will help raise awareness for parents about ADHD symptoms and available services.

TERMS OF REFERENCE:

- 1. Changes needed to address gaps in outcomes for vulnerable children, including those in rural and remote communities, Aboriginal communities, and culturally and linguistically diverse communities.**

While the NSW First Steps Aboriginal Children's Strategy (First Steps) seeks to improve health and education outcomes for First Nation's children in NSW the barriers to access services are still significant.

There is little evidence about the prevalence of ADHD and other neurodevelopmental conditions in First Nations people and the evidence for the effectiveness of health checks in improving health outcomes is mixed. However, the incidence of neurodevelopmental conditions and developmental delays is higher than in the non-indigenous population.

First Steps identifies several barriers which were also supported by the 2024 Closing the Gap report:

**Cultural Barriers:** Some families may be reluctant to engage with mainstream health services due to past negative experiences or a lack of cultural understanding and sensitivity to these services.

**Geographical Barriers:** Remote or rural communities may have limited access to healthcare facilities, making it challenging for families to access regular developmental checks.

**Financial Barriers:** Cost can be a significant barrier, especially for families experiencing financial hardship, as some services may not be covered by Medicare or other funding sources.

**Transportation Issues:** Lack of reliable transportation can make it difficult for families to travel to healthcare facilities for appointments.

**Language and Communication:** Language barriers can make it challenging for families to communicate with healthcare providers, leading to misunderstandings or lack of trust.

**Lack of Awareness:** Some families may not be aware of the importance of childhood developmental checks or the services available to them.

**Stigma and Discrimination:** Historical and ongoing discrimination and stigma can deter families from seeking healthcare services, including developmental checks.

#### **Proposed Solutions:**

##### **Awareness and Screening:**

Upskill early childhood educators about the value of identifying developmental delay and potential ADHD, and other NDDs.

Offer basic screening and referrals as part of routine health checks, encouraging vulnerable families to participate.

##### **Culturally Appropriate Support:**

Allocate resources from Closing the Gap recommendations to:

Raise awareness about ADHD among First Nations communities.

Train First Nations health workers to provide culturally sensitive support.

Fund research on specific barriers faced by First Nations families.

##### **Addressing Cultural Differences:**

Research the cultural understanding of "health" and "mental health" in First Nations communities.

Adapt mainstream standards to align with accepted local norms for child behaviour.

Design culturally sensitive resources and services, considering location, accessibility, and family needs.

##### **Educational Opportunities Gap:**

Recognise that limited educational opportunities can mask ADHD symptoms.

Develop strategies to identify ADHD despite potential differences in academic performance.

## **2. Barriers that affect parents' access that track their child's progress against developmental milestones.**

Barriers that affect parents' access to track their child's progress against developmental milestones, particularly in the context of neurodevelopmental conditions such as ADHD and others, are complex and encompass challenges including:

- ❑ An absence of meaningful, harmonised data collection that informs on developmental and diagnostic delays, and access to needs and supports. Newly established registries are aiming to address this gap (e.g., the Australian Child Neurodevelopment Registry managed and maintained by the University of Sydney.)
- ❑ Low engagement in treatment, communication barriers, such as a lack of clear information from healthcare providers or difficulty in understanding medical jargon, can hinder parents' ability to track their child's progress effectively.
- ❑ Co-occurring neurodevelopmental conditions: Parents may have difficulty accessing reliable and up-to-date information about developmental milestones and the specific needs of children with neurodevelopmental disorders.
- ❑ Limited awareness and knowledge of carers and parents - Parents may not be aware of the developmental milestones their child should be reaching, especially for children with developmental delays or neurodevelopmental disorders where milestones may differ.
- ❑ Lack of understanding/acknowledgement from clinicians, teachers and early childcare educators.
- ❑ Logistics: cost and financial difficulties, transportation issues, cost of assessments, interventions, and therapies can be a significant barrier for families, especially those with limited financial resources.
- ❑ Trust with professionals
- ❑ Stigma - stigma associated with neurodevelopmental disorders can lead to feelings of isolation and reluctance to seek help or engage with support services.
- ❑ Limited availability of services, long wait times, and geographical barriers can make it challenging for parents to access the necessary support and resources.
- ❑ Culturally and linguistically diverse: families from diverse cultures and speaking English as a second language often face challenges when accessing services such as lack of understanding/knowledge about neurodiversity, lack of English to communicate effectively with professionals, fear of being judged or removal of the parental authority.

### Strategies and Recommendations

- ❑ **Parent education and empowerment:** Provide parents with workshops, online resources, and support groups that offer information about ADHD and strategies for tracking their child's progress. Research by the University of Sydney suggests that caregivers currently have limited access to services and supports that would benefit them and their children, highlighting a substantial gap.
- ❑ **Telehealth and digital tools:** Use telehealth services and digital tools to improve access to assessments and consultations, reducing wait times and making it easier for parents to connect with healthcare providers. Research has shown that telehealth can be effective in diagnosing and identifying ASD and improving access to care.
- ❑ Researchers at the Brain and Mind Centre at the University of Sydney found **telehealth** was a feasible assessment tool for ASD in terms of administration, clinical experience, and information gained through the assessment process. It would be possible to translate this broadly to developmental checks.
- ❑ **Collaborative care:** Implement a collaborative care model that involves multiple healthcare providers, rather than the diagnostic burden being borne by paediatricians. Include broader allied health clinicians, and nurses along with early childhood educators, working together to provide comprehensive care for children, particularly those with neurodevelopmental conditions. In primary health settings, utilising appropriately trained nurses (and nurse practitioners) will improve access to developmental checks. Studies have shown high levels of patient satisfaction with nurse practitioner-

led care, including developmental checks. Patients appreciate the personalized care and attention they receive from nurse practitioners. Sydney Local Health District has recently recruited an ADHD/Mental Health nurse and is developing a model of care. AADPA is assisting with e-learning modules to aid upskilling of clinical staff

**Community outreach and education:** Conduct community outreach programs to raise awareness about ADHD, reduce stigma, and promote understanding. Engage schools, community centres, and other organizations to support parents and children with ADHD.

**Early intervention:** Focus on early identification and intervention for children with ADHD to address developmental delays and improve outcomes. Research suggests that early intervention can lead to better long-term outcomes for children with ADHD.

**Financial support:** Provide financial assistance or subsidies for assessments, treatments, and support services for families with children with ADHD. This can help alleviate financial barriers and ensure that all children have access to the care they need.

**Continued research and evaluation:** Support research efforts to further understand how early identification and intervention strategies can assist parents identify pathways for treatment.

### 3. Recruitment and retention of health professionals to address workforce shortages.

New South Wales is facing widespread shortages in clinical staff and healthcare workers. Shortages are particularly acute in key areas such as nursing, mental health, and rural and remote healthcare. These shortages have resulted in increased workloads, staff burnout, and difficulties in providing timely and quality care to patients. Addressing these shortages requires innovative approaches, including improvements to workforce planning, and enhanced training and education opportunities.

**Improved Training for Healthcare Staff:** Enhancing the training of healthcare staff, including paediatricians, psychiatrists, psychologists, general practitioners (GPs), nurses, and other allied health professionals, in the assessment and management of ADHD. Workforce planning in these disciplines will consider the increased recognition of ADHD and plan appropriately to meet the growing demand for ADHD services.

**Recognition of Training Priority:** Recognising the provision of training in the assessment and management of ADHD as a priority by universities and professional bodies in medicine, psychology, nursing, and allied health. Training should commence early in professional careers and be ongoing to incorporate new evidence and approaches.

Fostering the development of models of care that allow PHC providers to have an extended role in the assessment and management of conditions. Recent inquiries, such as the 2020 NSW Henry Review, and the 2023 Senate Inquiry into ADHD have indicated that relying solely on secondary care medical practitioners is unrealistic to meet the demand for even the most basic development checks.



#### **4. Funding for early intervention programs and screening to ensure children are given support for developmental issues, including telehealth and other models:**

Redesign services to triage development checks to enable pathways for different assessment and treatments within primary care and public sector secondary care services.

Increase funding for public services to deliver multidisciplinary approaches to assessment and management of neurodevelopmental conditions, like initiatives in Queensland such as the Integrated Care Innovation Fund and the Child Development Clinical Capabilities Framework that was developed in 2022-2023 through a collaboration by the Queensland Child and Youth Clinical Network.

Encourage closer collaboration between public and private sectors to provide a comprehensive approach to assessment for neurodevelopmental conditions. The inquiry could explore ways to incentivise private practitioners to contribute to this goal.

Change funding allocation and prescribing regulations to facilitate medication prescription for neurodevelopmental conditions in primary care settings.

Enhance awareness training for health professionals, educators, childcare providers, justice, welfare, and employment personnel on neurodevelopmental conditions, including funding for evidence-based training programs.

Develop initiatives to increase the number of skilled practitioners trained to deliver parent training programs and cognitive behavioural approaches for neurodevelopmental conditions.

Implement education and training programs to upskill psychiatrists in confidently prescribing medication for neurodevelopmental conditions.

Fund a coordinated approach to shared care models for neurodevelopmental conditions in Australia. Integrate support and treatment services into treatment pathways and packages of care to align with multimodal care recommended for individuals with neurodevelopmental conditions.

Examine funding mechanisms to allow professionals to allocate the time required for comprehensive and accurate assessments for neurodevelopmental conditions.

Introduce targeted subsidies for low-income families of individuals with neurodevelopmental conditions to ensure access to necessary medication.

#### **Any other matters**

Developmental checks alone are not sufficient to detect every child with a learning disorder or neurodevelopmental condition, such as ADHD. Inevitably, some children will fall through the cracks and their ADHD will become apparent at a later stage in the classroom. Schools are therefore a vital resource for capturing children who are missed during early routine health checks, and it is essential that schools are engaged in the discussion about their role in supporting children with ADHD.

There is evidence that ADHD presents differently in girls than it does in boys and diagnostic criteria do not adequately consider this<sup>11</sup>. As a result, girls may be more likely to be undiagnosed, misdiagnosed, or have delayed diagnosis.

Girls may also have unique support needs due to their differing presentation and the greater association between ADHD in girls and certain co-occurring issues, such as intellectual disabilities, suicidal behaviours, and substance use disorders. Funding for further research into ADHD in young girls is crucial to ensure they

receive the earliest possible diagnosis and appropriate support during early developmental stages to improve long-term outcomes.

Importantly, our group realises the need to involve individuals with lived experience in all stages of the research process, from idea generation and development to communication and dissemination of results. Individuals with lived experience are represented within our committees and engaged at all stages of our work, ensuring a collaborative, genuine partnership.

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**Attachment included with submission**

Australian ADHD Professionals Association, [Submission to the Senate Standing Committee on Community Affairs: Barriers to consistent, timely and best practice assessment of Attentive Deficit Hyperactivity Disorder \(ADHD\) and support services for people with ADHD](#), 9 June 2023