

**Submission
No 25**

IMPROVING ACCESS TO EARLY CHILDHOOD HEALTH AND DEVELOPMENT CHECKS

Organisation: Autism Awareness Australia

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Parliament of NSW
Legislative Assembly
Committee on Community Services
Sydney NSW 200

Attention: Committee Members - Inquiry into Improving access to early childhood health and development checks

Autism Awareness Australia welcomes the opportunity to prepare a submission for the committee in the hope that it will contribute to the Inquiry into Improving access to early childhood health and development checks.

ABOUT US

Founded in 2007, Autism Awareness Australia (AAA) is a not-for-profit autism education and awareness organisation. Our goal is simple: To improve the lives of all Australians on the autism spectrum and the families who love them.

As the country's leading voice for autism families, Autism Awareness Australia aims to spark positive change by increasing education and understanding of autism in Australia.

Autism Awareness's campaigns and events have reached millions of Australians. We have delivered most of those programs free of charge across the country, including in rural and regional communities.

For 17 years, Autism Awareness Australia (AAA) has been recognised as a trusted organisation, offering invaluable information and resources to individuals with autism and their families. We've established ourselves as Australia's leading authority on autism and related conditions. Our independence and an unwavering commitment to quality have cemented our respected reputation in the community. Today, we proudly oversee the largest autism network and database in the country, with a vibrant community of over 175,000 active followers.



Autism Awareness Australia has long been led by parents of children with autism. Our Executive Director has a child with autism, as does 65% of our Board. Many contributors and volunteers over the years have either had autism or were the parents of children with autism.

OVERVIEW

In the broader context of improving access to early childhood health and development checks for all children, it becomes particularly vital to consider the impact on those with autism. Universal access to these checks plays a critical role in identifying developmental delays across the board, but for children with autism, the stakes are especially high. The fact is, while early intervention is beneficial for any developmental delay, its effect is profoundly transformative for autism. Timely detection and subsequent support can radically improve communication, social skills, and learning abilities. Unfortunately, the current reality is that many children with autism do not receive a diagnosis until significantly later than their peers with other developmental challenges. This delay in diagnosis means missing early intervention opportunities during a crucial developmental window. It's not just a delay; it's a period of stagnation where skills that could have been developed remain untapped.

Consequently, these children often face more significant challenges when starting school, a critical stage where early deficits can lead to long-term educational and social implications. Therefore, enhancing access to early health checks for all children is not just a matter of equity; it has profound implications for those with autism. It's about ensuring that every child, regardless of their developmental condition, can reach their full potential from the earliest possible moment.

OUR SUBMISSION RELATES TO THE FOLLOWING TERMS OF REFERENCE:

1. Changes are needed to address gaps in outcomes for vulnerable children, including those in rural and remote communities, Aboriginal communities, and culturally and linguistically diverse communities.
2. Barriers that affect parents' access to routine health and development checks that track their child's progress against developmental milestones.



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

Issues:

- Families don't have clear direction on what early childhood health and development checks are available through Community Health Centres beyond the first few checks after birth.
- If parents are concerned about their child's development, there are long waitlists across many state public health assessment centres, leaving many families to wait for months to have their child assessed.
- There is currently no funding available for diagnostic assessment. As such, parents either wait on the public assessment waitlists or try to find the funds for often expensive private diagnostic services.
- GP's often miss the early signs of autism, and many minimise the concerns of anxious parents and often don't refer on until pushed further.
- Delays by Paediatricians with the 'wait and see' approach. Often, parents will be told to return for a second observation six months later.
- In our recent Autism: What Next? National Survey, 60% of parents reported unnecessary delays in getting their child a diagnosis and 78% of families reported wait times to be a factor in this.
- We know the importance of early intervention for young children with autism, so reducing the age of early diagnosis should be a priority.
- Need for greater understanding and training for medical and allied health professionals to recognise autism through numerous age and gender profiles, not just what autism looks like in toddlers.
- There is currently very limited access to quality early intervention for children.
- The NDIS' focus on 'Choice and Control' is imperative. Still, parents need guidance and restrictions to only use NDIS funds for early intervention supports, which are evidence-based and individualised for the child.
- There remain very few early intervention options for rural and regional children.



- Early interventions are not 'all created equal' and interventions in very young children should focus on skill development and positive behaviour support.
- Workforce capacity limitations have led to a shortage of placements in evidence-based early intervention services across Australia.

Recommendations:

- Improved communication from NSW Health to new parents during their stay in hospital when their child is born outlining the importance of regular health and developmental checks, and they are available and free through the Community Health Centres.
- The NSW Digital Baby Book provides a digital alternative to the existing paper-based My Personal Health Record (Blue Book). Service NSW could develop a mechanism that includes reminders to families of when a child's regular health and development checks are due. Ideally, it should be at the ages identified in the Blue Book.
- Community Health Nurses should be better trained in the early signs of autism and a developmental inclusion checklist to be included in newborn's Personal Health Record books (Blue Book).
- In the My Personal Health Record (Blue Book), Developmental milestones are listed as a guide, but the checklists focus more on medical conditions such as sight and hearing.
- Rural and regional families need to have access to Community Health Nurses and developmental assessments via Telehealth by clinicians who specialise in remote diagnostic services.

Kind Regards



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Autism Awareness Australia