Submission
No 41

INQUIRY INTO FOUNDATIONAL AND DISABILITY SUPPORTS AVAILABLE FOR CHILDREN AND YOUNG PEOPLE IN NEW SOUTH WALES

Organisation:	Autism Awareness Australia
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Autism
Awareness
Australia

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Select Committee on Foundational and Disability Supports
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Attention: Committee Members - Inquiry into foundational and disability supports available for children and young people in New South Wales

Executive Summary

Autism Awareness Australia (AAA) notes the inherent difficulty in commenting comprehensively on foundational supports, as these supports remain largely theoretical and undefined at this point. The concepts of 'general foundational supports' and 'targeted foundational supports' lack clear definitions and implementation frameworks. Consequently, our submission provides insights and recommendations based solely on the limited information currently available, without full clarity on the intended function of foundational supports as an alternative to individualised NDIS funding.

We strongly emphasise the critical importance of effective early intervention services for children with autism spectrum disorder and developmental disabilities. Timely, expert-driven, autism specific early intervention has profound, life-changing impacts. Australia and its states and territories lack a comprehensive and effective early intervention system for the growing number of autistic children and those with developmental delay, with existing frameworks remaining inadequate, fragmented, and heavily influenced by geography and family resources.

It is imperative that children with more significant disabilities continue to access individualised NDIS funding specifically for autism-focused early intervention to effectively address their complex needs and improve lifelong outcomes. For children with developmental and learning delays who might not qualify for individualised funding, any foundational support system must prioritise targeted interventions that are evidence-based, adequately funded, and demonstrably effective.

In February/March 2025, we conducted a comprehensive National Autism Parent/Carer Survey, gathering insights from over 1,200 respondents. The findings published in our April 2025 report significantly inform the perspectives, concerns, and recommendations outlined in this submission.

Responses to the Terms of Reference:

(ToR 1a): Role and Impact of Services and support on child's development

While typically developing children naturally learn and thrive within their everyday family and community environments, children with autism and developmental disabilities require specialised, individualised interventions to effectively address specific developmental challenges and barriers. Without timely and adequate early intervention supports, these children risk significant, ongoing developmental setbacks. Such setbacks can negatively affect their educational experiences, ultimately limiting their ability to lead independent, fulfilling lives as adults. So, the critical role of early intervention for children with developmental concerns, delays, and disabilities cannot be overstated.

Targeted early interventions must be grounded in robust evidence-based practices, clearly defined intervention goals, and measurable outcomes. It is essential that these interventions are tailored to the unique needs of each child, particularly recognising and accommodating the distinct needs of children with autism spectrum disorder compared to those experiencing general developmental delays. Ensuring this differentiation within the foundational support system will help deliver more effective outcomes and maximise developmental potential for all children involved.

(ToR 1b): Availability, Accessibility, and Effectiveness of Supports

In the decade since the introduction of the NDIS, service provision for children with developmental disabilities has largely shifted to being funded and delivered through the Scheme. As a result, State-funded services have significantly diminished, leaving a fragmented landscape with limited infrastructure for foundational supports outside the NDIS. It will take time for the States to rebuild their capacity in this area.

This lack of state-level investment presents a significant barrier to the timely and equitable development of foundational supports. The issue is particularly pronounced in regional and rural communities, where services are extremely limited or non-existent. Even in major metropolitan areas, access remains inconsistent and insufficient to meet current demand.

At present, there are no best practice models for foundational supports operating at scale within NSW. Despite more than a decade of the NDIS, Australia still lacks an evidence-based, nationally endorsed early intervention model for autistic children and those with developmental delay. To address this, states must actively seek guidance from independent experts with deep clinical and practical experience—voices that have too often been overlooked or excluded from previous NDIS program design and decision-making processes.

The absence of scalable, evidence-based frameworks continues to hinder efforts to deliver consistent, high-quality early intervention and support services across the state. Addressing this gap will require significant investment—and a collective willingness to acknowledge that building an effective system won't come cheaply. It's time to make the necessary commitment and invest in doing this properly.

(ToR 1c): Diagnostic Services – Gaps and Recommendations

Access to assessment and diagnostic services in New South Wales remains significantly inadequate. Findings from Autism Awareness Australia's recent **2025 National Autism Parent and Carer Survey** highlight critical issues: 32% of families waited more than two years for diagnostic assessments, over 50% waited more than one year, and the proportion of families receiving a diagnosis within six months drastically dropped to just 26% in 2024. Extended wait times exacerbate stress for families and significantly delay children's access to vital early intervention supports.

Our survey further revealed that 76% of families relied on private providers for autism assessment and diagnostic services, while only 20% accessed government-funded options. This reliance on private sector providers indicates a desperation among families to obtain timely support for their children, often placing significant financial strain on already-pressured families.

The economic and social costs of delaying diagnostic services are substantial. It is essential to expedite access to diagnostic assessments to ensure that children swiftly receive the appropriate individualised or foundational supports they require.

Additionally, improving general foundational supports, including educating and informing parents and carers about the importance and benefits of timely diagnostic assessments, is crucial. Proactive communication and streamlined referral pathways can significantly reduce barriers and help families navigate these essential services more effectively.

(ToR 1d): Addressing Gaps in Early Intervention Access

Significant gaps and barriers currently limit children's access to effective, evidence-based early intervention in Australia. These gaps span multiple critical areas, notably the fragmented nature of early intervention services, geographical disparities, and high costs. A major concern is the critical shortage of skilled professionals and qualified service providers delivering evidence-based early intervention supports.

Additionally, families often lack a clear understanding of the critical importance of early intervention, the necessity of early action when developmental delays are identified, and how to select evidence-based interventions. Families from socio-economically disadvantaged and CALD backgrounds often face additional barriers, including limited access to navigation tools, culturally adapted information, and language-appropriate resources.

Australia's current lack of an early intervention framework and system inadequately addresses these significant issues, leading to disparities in child outcomes based on location and family resources. It is imperative that foundational support systems incorporate comprehensive solutions. Effective navigation tools must be developed to clearly guide families from initial diagnosis through to appropriate early intervention services, reducing their reliance on often commercially driven market providers. Helping families to navigate these complex systems should be a priority.

Furthermore, New South Wales urgently requires a strategic workforce development plan to address the critical imbalance between workforce supply and service demand. Addressing these gaps and enhancing the effectiveness of early intervention services will yield substantial long-term benefits. By failing to provide a child with timely access to quality early intervention services, we not only disadvantage the child directly but also place considerable strain on their extended family, often restricting a parent's capacity to maintain full-time employment. Additionally, inadequate early intervention inevitably places increased demands on other government services and systems, which are required to manage challenges that could have been more effectively addressed through earlier supports. Early investment in effective, evidence-based intervention ensures improved lifelong outcomes for children, presenting a clear cost-benefit advantage for both state and federal governments.

(ToR 1f): Best Practice Examples and Models

When considering best practice models in early childhood intervention and child development services—particularly those operating successfully outside of New South Wales—it is vital to challenge the persistent notion that a single, one-size-fits-all solution can address the complex and diverse needs of children with developmental delay, including autism.

Autism, by definition, is a spectrum, and the supports required must be equally varied and responsive. What works for one child may not be appropriate—or effective—for another. This principle holds true not only within autism-specific services, but also across the broader population of children with developmental challenges. The best models, both internationally and interstate, reflect this by embracing flexible, individualised, and family-centred approaches, supported by a multi-disciplinary network of professionals.

What New South Wales must now do is move away from chasing singular, scalable 'solutions' and instead invest in a spectrum of evidence-based programs that reflect the full diversity of need. This is how meaningful outcomes are achieved—through layered, adaptable, localised systems that offer choice and continuity.

Furthermore, it is essential to reclaim the meaning and rigour of "evidence-based practice." In recent years, the term has been diluted and misused—often reduced to anecdotal endorsement or popularity, rather than grounded in clinical research, long-term data, and peer-reviewed outcomes. True evidence-based practice requires methodological integrity, clear outcome measurement, and ongoing evaluation. Few people in policymaking or program design circles today appear to grasp or apply this standard fully.

To deliver meaningful outcomes, New South Wales must invest in evidence-based, diverse, and adaptable service models that reflect the complexity of developmental delay, rather than relying on oversimplified or one-size-fits-all solutions.

(ToR 1g): Workforce Issues: Demand, availability, quality and capacity

Addressing workforce issues must be recognised as one of the most significant barriers for state governments when developing foundational supports. The existing National Disability Insurance Scheme (NDIS) system already faces substantial workforce challenges, including shortages of adequately skilled professionals. Introducing a state foundational support system outside the NDIS will further amplify the demand for skilled staff and clinicians.

It is crucial for state governments to implement comprehensive workforce strategies in collaboration with universities, allied health professionals, and relevant professional bodies. These strategies should focus on attracting, training, and retaining qualified individuals capable of delivering evidence-based supports to children with developmental delays. Currently, there is a significant mismatch between workforce availability and the growing demand for specialised early intervention services.

Increasing workforce capacity must not compromise the quality of care provided to children. It is essential to ensure that the foundational support system employs well-trained, adequately supervised, and appropriately skilled personnel. The current situation with teacher aide programs in public schools, where low-skilled workers often deliver supports, highlights the risks associated with inadequate training and supervision.

Professional development and training incentives should be integral to workforce development plans, ensuring ongoing skill enhancement, retention of qualified personnel, and consistent quality in service delivery. Effective workforce planning and targeted investments in professional training and development are critical to successfully addressing the workforce challenges inherent in building an effective foundational support system.

(ToR 1i): Other Relevant Matters

A critical issue related to the development of foundational supports is the significant reduction in funding available to non-government organisations (NGOs) and advocacy groups working in this space. During the transition to foundational support, there has been a reduction in funding opportunities from the Information, Linkages, and Capacity Building (ILC) previously provided under the NDIS. Many grant programs formerly accessible through the ILC have diminished or ceased entirely. Consequently, numerous organisations now face severe underfunding and uncertainty regarding their viability.

Without sustained funding, these NGOs and advocacy organisations risk closure, eliminating their essential contribution to the development of the foundational support system. These groups possess invaluable resources, intellectual property, and lived experience, all vital to informing effective foundational support systems. Their expertise and ongoing engagement are crucial to the state's successful implementation of foundational supports. Continued delays and funding uncertainties between state and federal governments threaten the very existence of these critical organisations.

Conclusion and Recommendations Summary

We are deeply concerned that the pace of NDIS reforms has not allowed states sufficient time to plan, develop, and implement a robust system of foundational supports. These supports are critical to ensuring that children with developmental delay and disability—particularly autistic children—receive the help they need early.

Rushing this process risks creating fragmented, under-resourced systems that will fail the very children they are intended to support. Without careful planning, consultation, and investment, many children will go without timely intervention, with long-term consequences for their development, wellbeing, and future participation in society.

We strongly recommend a more measured, inclusive, and evidence-informed approach that allows for proper design, piloting, and scaling of foundational supports in partnership with families, professionals, and the community.

Autism Awareness Australia stands ready to contribute our experience and expertise to support New South Wales in getting this right.

About Autism Awareness Australia (AAA)

Founded in 2007, Autism Awareness Australia (AAA) is a national, not-for-profit organisation dedicated to autism education, advocacy, and awareness. Our mission is clear and compelling: to improve the lives of Australians on the autism spectrum and the families who support them. For over 18 years, we have served as a trusted voice and resource, driving meaningful change through impactful education and increased public understanding of autism.

As Australia's peak body for autism families, we are uniquely positioned to represent and advocate for the autism community effectively. Our campaigns and events have reached millions, significantly raising awareness and fostering greater societal understanding of autism across the nation.

AAA's strength and credibility come from our genuine lived experience—parents of autistic children have consistently led our organisation. Currently, our Executive Director, 80% of our Board, and 60% of our staff are parents of autistic children. Additionally, numerous autistic individuals and parent volunteers have significantly contributed to our work, ensuring authentic representation and meaningful insights. Our experienced executive team, many with years of dedicated service, brings both professional expertise and direct lived experience.

We proudly manage Australia's largest autism-focused network and database, with an engaged and vibrant community exceeding 215,000 active followers. This extensive reach empowers us to effectively engage and support families across the country, providing invaluable resources, support, and advocacy.