Australian Autism Alliance

Submission to Inquiry into Thriving Kids initiative

Leave no child behind: Designing an accountable integrated ecosystem to sustain a Thriving Kids and NDIS.

We acknowledge the First Nations and Traditional Owners of the land, sea and waterways and pay respects to Elders past, and present and recognise those whose ongoing effort to protect and promote Aboriginal and Torres Strait Islander cultures will leave a lasting legacy for future Elders and leaders.
We recognise the enduring connection that First Nations peoples have to land, waters, culture, and community. This land was, is, and always will be Aboriginal land.

We acknowledge the individual and collective expertise of those with a living or lived experience of disability, as well as the lived experience of people who have been carers. We recognise their vital contribution at all levels and value the courage of those who share their unique perspective for the purpose of learning and growing together to achieve better outcomes for all.

**All verbatim quotes and statistics are sourced from the Australian Autism Alliance's "Thriving Kids" survey conducted in September 2025.*

Contents

1.0 Introduction and Context

1.1 About the Australian Autism Alliance

www.australianautismalliance.org.au

The Australian Autism Alliance (the Alliance) welcomes the Committee's Inquiry and thanks you for your time and dedication to securing thriving futures for all citizens.

The Alliance was established in 2016 and aims to improve the life chances of autistic people and facilitate collaboration within the autism community. The members represent a cohesive national network of key organisations with a diverse focus on autism – that is led by autistic people, advocacy groups, peak bodies, service providers, and researchers.

We reach over half a million people through our communication channels and provide support to people with autism across the lifespan. Most importantly, our work is informed by Autistic people and the Australian Autism community.

The Alliance is a funded Disability Representative Organisation (DRO) advocating for a Strong Voice for Autism, and supports Australian government (at all levels) in various roles and representations, including: DSS Disability, Representative Organisation, the NDIA Autism Advisory Group, the NDIA DRCO Co-Design Advisory and Reform groups, NDIS Commission Disability Sector Consultative group, National Autism Strategy Oversight Council member, and National Health and Mental Health Roadmap for Autistic people.

1.2 Thriving Kids Inquiry Community Pulse Survey

The Alliance issued an online survey during September 2025, gathering opinions and suggestions from Autistic people and the Australian autism community. This survey was released prior to the announcement of the Inquiry. The Alliance has used the survey responses to inform this submission.

The context provided for the survey was for opinions to help guide decision-makers on issues that affect Autistic people and their families.

We have undertaken a preliminary analysis to inform this submission. The way the survey responses have been included in this submission is as follows:

1. Section 4 (outlining the key themes, unfiltered quotes from respondents and calls to action)
2. Section 5 (key themes and unfiltered quotes from respondents to inform responses to the Thriving Kids Parliamentary Inquiry Terms of Reference six questions)
3. Appendix 1 provides a profile of respondees and a high-level summary of some of the specific questions in the Alliance Community Pulse Survey.

Other contributions to inform this submission are from the Alliance membership.

A separate full survey report will be provided when complete.

2 Executive Summary

Community sentiment
In September this year, we conducted a national survey on the Government's proposed *Thriving Kids* program. Our survey, responded to by Autistic people, families, and allies nationwide, revealed overwhelming concern and a critical lack of trust in the proposed Thriving Kids program.

The message was unmistakable: **91% of respondents are opposed (60%) or undecided (30%)**. Anxiety and distress across the Autistic community are palpable. Families told us bluntly that they fear the transition will be chaotic and damaging, with serious risks arising from a lack of transparency and co-design, potential harm and loss of support, workforce gaps, weak evidence, and inequitable outcomes.

There were **9%** that indicated they were **"majority in favour",** who were mainly educators and health professionals. The community saw some potential if the program is **properly designed and adequately funded** (including the 9%).

Across the community, there is recognition that reform is needed—but **not in its current form**. At the time of writing this submission, Australian Autistic and Autism Community Voices are calling on Government to reset – **to pause Thriving Kids and rebuild it on the right foundations**, with lived experience at the centre.

The risks are real
This fear is grounded in experience. People have been here before.

The NDIS was created because children with developmental disabilities, including autism, were missing out on early intervention and adequate support. At that time, the Productivity Commission warned that failure to invest early would create long-term costs for families, the economy, and society.

The Thriving Kids inquiry is occurring during a period of unprecedented system pressure. Current proposals risk repeating history by diverting children into mainstream systems that multiple reviews—the Senate Inquiry into Autism, the Disability Royal Commission, and the NDIS Review—have already found to be **broken, under-resourced, and lacking accountability**. These reviews highlighted people being handballed between systems, falling through gaps, and experiencing inconsistent or inadequate support. Implementation plans to address these failures remain in their infancy.

Families have told us plainly that they fear their children will be placed in systems that are under-trained, under-resourced, and unaccountable. They fear being handballed between broken systems, and they are deeply concerned about language that frames their children as burdens or support as "wasteful." This framing undermines the core principle of the NDIS: **individualised, needs-based support**.

Autism support needs vary widely and are context dependent. A child may thrive in one environment and require significant support in another. Yet families are being asked to transition into an undefined system with no clear guarantees that support will be suitable, affordable, accessible, or available—precisely when early intervention matters most.

This fear is intensified by scarcity: concerns that needs will be capped, that the right support will not be available at the right time, and that systems will not be equipped to respond appropriately.

As the Senate Inquiry into Autism found, the greatest barrier to inclusion is a lack of autism knowledge, skills, and confidence across systems. Outcomes are stark—Autistic preschoolers are **10 times more likely to be permanently excluded from preschool**.

Thriving Kids also does not constitute robust NDIS reform. By targeting the youngest and most vulnerable children, it risks shifting costs onto other government systems rather than addressing underlying failures.

What works—and what is at stake
When families know there is a reliable, safe, and personalised pathway—one that is inclusive but able to escalate specialist support at the right time—they do not cling to scarcity. They can participate, contribute, and thrive.
This proposal arrives amid a cost-of-living crisis, housing insecurity, and widespread reports of negative NDIS impacts following recent legislative changes. Against this backdrop, families are being asked to let go of existing supports without safety nets in place.

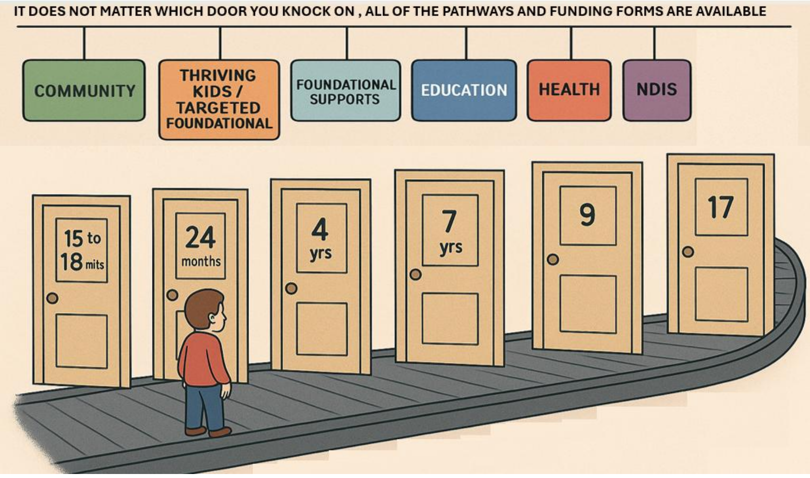
Solutions: the path forward
This should not be an either/or proposition. Early support is not a luxury—it is a right. We must not create a two-tier system where only children with the highest needs remain on the NDIS while others are pushed into mainstream systems that have historically failed them.

Like trapeze artists, families need safety nets in place before being asked to let go. As Minister Butler has said, “There is much work to be done.” We agree—but short-term fixes must not come at the expense of long-term outcomes.

Autism is a lifelong neurodevelopmental difference. A generalised model without funded specialist escalation through the NDIS may save money now, but it will cost far more later through education exclusion, mental health crises, family breakdown, and lost workforce participation.

Evidence consistently shows that **early, targeted investment delivers long-term returns** when implemented well. Domestic and international experience demonstrates that sustainable, whole-of-community approaches outperform fragmented systems.

A universal system must ensure that government takes responsibility for triage, guaranteeing that at the **Right Door**, children and families can access **appropriate, available, affordable, and accessible supports**, in the **right quantity**, from the **right expertise**, and **fit for the person**.



What Government must do
Thriving Kids could be a once-in-a-generation opportunity to design reform properly—but only if rights, co-design, evidence, and safeguards come first. Government must build on proven models, avoid arbitrary restrictions, and ensure transition plans include clear accountability.

Without this, children risk transitioning into inadequate systems, turning prior NDIS investment into sunk costs and increasing future demand across education, health, and social services.

Our community is clear: reform is needed. We all want the NDIS to be sustainable and for Australia's economy to thrive. Social licence is essential to the Scheme's future.

But not like this.

We call for Thriving Kids to be **paused and rebuilt—together—with respect, transparency, and lived experience at the centre**.

To go fast is to go slow. There are a number of critical recommendations that we have summarised in a table below that emerge in response to the Terms of Reference. We have also flagged the 15 immediate actions to help turn the community sentiment from fear into trust and scepticism into constructive partnership so every child can thrive in the table below and Appendix 3.

At the heart only a Thriving Kids program co-built *with* Autistic people and their families—not *for* them—will deliver the thriving futures it promises.

3 Summary of Recommendations and Traceability Matrix to Response

Legend: ↻ **Immediate steps to restore trust & create partnership**

No.	Recommendations	Source	Legend	Parliamentary Inquiry on Notice
TOR 1: EXAMINE EVIDENCE-BASED INFORMATION AND RESOURCES				
1.	**Build trust through regular, transparent, and accessible grass-roots parent-facing information**	Section 5.1		
2.	**Reset towards co-production of practical supports with Autistic people and autism community members as the primary recipients of the Thriving Kids program**	Section 5.1	↻	
3.	**Guarantee Early Identification and Referral**	Section 5.1 & Appendix 5	↻	Early Years Pathway
4.	**Prioritise Parent and Families Empowerment**	Section 5.1		
TOR 2: EXAMINE EFFECTIVENESS OF CURRENT (AND PREVIOUS) PROGRAMS AND INITIATIVES				
1.	**Baseline and Evaluate before reform**	Section 5.2	↻	
2.	**Align with the National Autism Strategy First Action Plan commitment to review what already exists**	Section 5.2	↻	
3.	**Define success and measure it**	Section 5.2		
4.	**Guarantee equitable access**	Section 5.2		
5.	**Fund collaboration between schools and therapists, and support children outside mainstream.**	Section 5.2		
6.	**Strengthen mainstream services with Individualised and affirming approaches.**	Section 5.2		
7.	**Ensure ethical and neuro-affirming practice**	Section 5.2		
8.	**Implement the Essential Principles for Reform as Preconditions and Evaluation Criteria**	Section 5.2 & Appendix 4	↻	
TOR 3: EQUITY AND INTERSECTIONAL ISSUES				
1.	**Embed binding equity safeguards to ensure children in marginalised groups are not left behind** ○ Undertake demographic-disaggregated impact modelling ○ Genuine Co-production with intersectional groups ○ Plan, fund and manage proactively (including iteratively) the Thriving Kids rollout and implementation to prevent disadvantaging marginalised groups. ○ Community advisory groups are resourced and embedded in governance	Section 5.3		

No.	Recommendations	Source	Legend	Parliamentary Inquiry on Notice
	○ Anti-Discrimination Measures: Implement safeguards to prevent systemic discrimination.			
2.	**Make Information, supports and Services Culturally Safe and Accessible** ○ Provide culturally appropriate information in multiple languages and fund interpreters. ○ Provide incentives for healthcare providers to work in remote areas. ○ Collaboration with First Nations and CALD Disability Representative Organisations to provide support and advocacy for families navigating the program	Section 5.3		
3.	**Workforce Development** ○ Invest in training, recruit and support First Nations and CALD professionals as part of workforce development. ○ Cultural and Equity Training Investment.	Section 5.3		
4.	**Invest in culturally safe Place-Based and Flexible Support Delivery Models** ○ Fund community hubs and outreach programs including in remote areas, employing First Nations/ CALD staff as cultural liaisons. ○ Avoid "one size fits all" designs—meet families where they are with culturally relevant approaches.	Section 5.3		
5.	**Accountability and Transparency** ○ Require all Thriving Kids programs to demonstrate how they will reach and serve marginalised groups and monitor outcomes.	Section 5.3		
TOR 4: GAPS IN WORKFORCE SUPPORT AND TRAINING				
1.	**Plan and Pilot First:** Recommend a pause to Thriving Kids until Autistic-affirming best practices in training in care are clearly defined with outcome measures through the NAS	Section 5.4		
2.	**Develop a National Workforce Development Strategy including a capacity audit competency framework and funded training plan** a) Create a national workforce plan with training subsidies, rural incentives, and specialist recognition b) Develop a tiered competency framework c) Require a national workforce capacity audit and implement a funded training plan before any large-scale transfer of services. d) Develop Multidisciplinary and Community-Based Models e) Protect Specialist Expertise	Section 5.4		
TOR 5: DRAWING ON DOMESTIC AND INTERNATIONAL POLICY EXPERIENCE AND BEST PRACTICE				
1.	**Review, Evaluate and adopt domestic and international lessons:**	Section 5.5		

No.	Recommendations	Source	Legend	Parliamentary Inquiry on Notice
	a. Systematic review of international literature and Australian pilots. b. Seek comparative evidence on: (a) successful integrated early-support models internationally, (b) transitions off disability schemes and safeguards used elsewhere, and (c) evaluation frameworks showing no net loss of support for vulnerable children. c. Plan the shift towards needs-based right based framework of supports (align with CRPD Article 26) instead of diagnosis-based ones			
2.	**Mandate neurodiversity-affirming standards**	Section 5.5		
3.	**Time Required for Improvement**: therapy should not be prematurely withdrawn based on short-term results.	Section 5.5		
4.	**Co-design and governance** ○ Establish paid, representative co-design panels (autistic people, families, priority groups in NAS ○ Reform advisory structures to include lived-experience-led models, rather than just expert-led. ○ Establish interfaces with existing groups	Section 5.5		
5	**Staged Pilots, Independent Evaluation and Public Reporting**	Section 5.5		
6	**Development of Guiding Principles**	Section 5.5 & Appendix 4	⟲	Establish Trust & Partnership with community
ToR 6: IDENTIFY MECHANISMS THAT ALLOW A SEAMLESS TRANSITION				
1	**Develop a Whole-of-System Reform Roadmap**	Section 5.6	⟲	

2	**Implement a Vertical and Horizontal Integration Accountability Transition Plan**
	○ Individual transition plans
	○ Concrete transition guarantees
	○ Education-specific transition supports
	○ Clear accountability levers at three levels:
	  ○ Federal cross-portfolio level
	  ○ State/Territory and local system level
	  ○ Individual child level
		Section 5.6 & Appendix 5	⟲	

3	**Establish Formal Safeguards During Transition** ○ Formal government-led dispute resolution and complaints mechanisms ○ Guaranteed funding continuity ○ Legislative “no-gap protections”	Section 5.6	⟲	
4	**Introduce a System “Superhighway” With On- and Off-Ramps** ○ Early Diagnosis and Access Pathway establishing a nationally consistent, neurodiversity-affirming framework ○ Develop a shared profile passport system	Section 5.6 & Appendix 6		

No.	Recommendations	Source	Legend	Parliamentary Inquiry on Notice
5	**Develop Guiding Principles for Transition**	Section 5.6 & Appendix 4		
6	**Establish Developmental Hubs**	Section 5.6		
7	**Mandate Workforce Training**	Section 5.6		
8	**Fund Family Navigators and Lived-Experience Advocates**	Section 5.6		
9	**Build on What Already Works**	Section 5.6		
10	**Strengthen Independent Autism Advocacy**	Section 5.6		
11	**Simplify Processes and Increase Transparency**	Section 5.6		
12	**Ensure Continuity Across Life Stages -** Develop a Stage 2 roadmap that ensures continuity across key life stages	Section 5.6		
13	**Monitor and Enforce Outcomes**	Section 5.6		
	Fifteen Clear Government Steps to help build trust and move towards a constructive partnership in the timeframe	Appendix 3	↻	Establish Trust & Partnership with community
	Our 11 Essential Principles for Reform	Appendix 4	↻	Establish Trust & Partnership with community
	Accountable Integrated Governance with A Safe Vertically and Horizontal Transition Plan	Appendix 5	↻	Establish Trust & Partnership with community
	Early Diagnosis and Access Pathway – Neurodevelopmental Superhighway	Appendix 6		Early Years Pathway
	After-School Care (OSCH) Integration	Appendix 7		Afterschool Care Models

5 A Strong Voice for Autism: The Alliance's Community Pulse survey on the Thriving Kids program (Sep 2025)

During September 2025, the Australian Autism Alliance invited Autistic people and the autism community to share their opinions of, and suggestions for, the Thriving Kids program. This was prior to the Parliamentary Inquiry being released. A summary is provided below of the overall sentiment and the calls for action.

5.2 Overall Sentiment

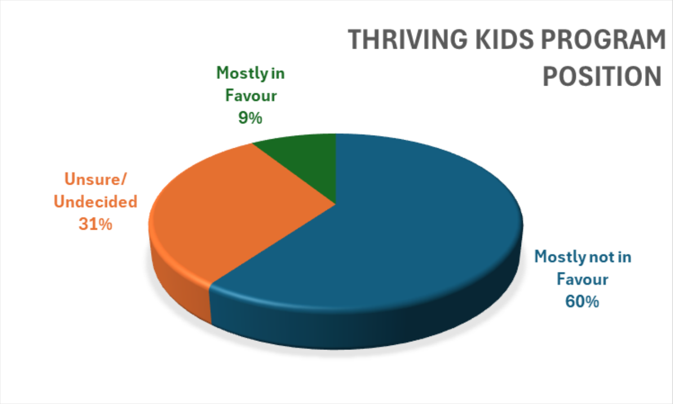
At the time of writing this submission, our survey had drawn 429 responses in just two weeks. Our survey, which was responded to by Autistic people, families, and allies nationwide, revealed overwhelming concern and a critical lack of trust in the Thriving Kids program. The majority of respondents **(91%) were mostly not in favour** of the program **or were undecided about it** (due to the lack of accessible information available). Nine percent were mostly in favour of the program. The Alliance's survey also collected the rationale for their opinions.

Autistic people and the autism community's anxiety and distress are palpable.

"We are worried. We are tired. That's all."

"I fear for what the future looks like."

"We've been promised the world too many times. Hope is only a flicker we reserve for our children……..."



Families told us bluntly that they fear this transition will be chaotic and damaging. Families are clear: Thriving Kids will only succeed if it builds on proven models, avoids arbitrary restrictions, and restores trust through co-design, transparency, and affirming, individualised supports.

"It could destroy my children. After years of building rapport and progress, instability could be disastrous."

Our community is clear: Reform is needed. But not like this. At the time of writing this submission

Australian Autistic and Autism Community Voices are calling for the Government **to reset by pausing** Thriving Kids **until it is rebuilt on the right foundations**.

The response was also united in its demand for **transparent, equitable, and genuinely co-designed** reform of the NDIS and localised Foundational Supports.

Of the **9% mostly in favour** of the program almost all who saw potential in the program concept emphasised that positive outcomes would depend on successful program design and implementation, adequate funding and genuine co-design in partnership with individuals and families with lived experience of autism.

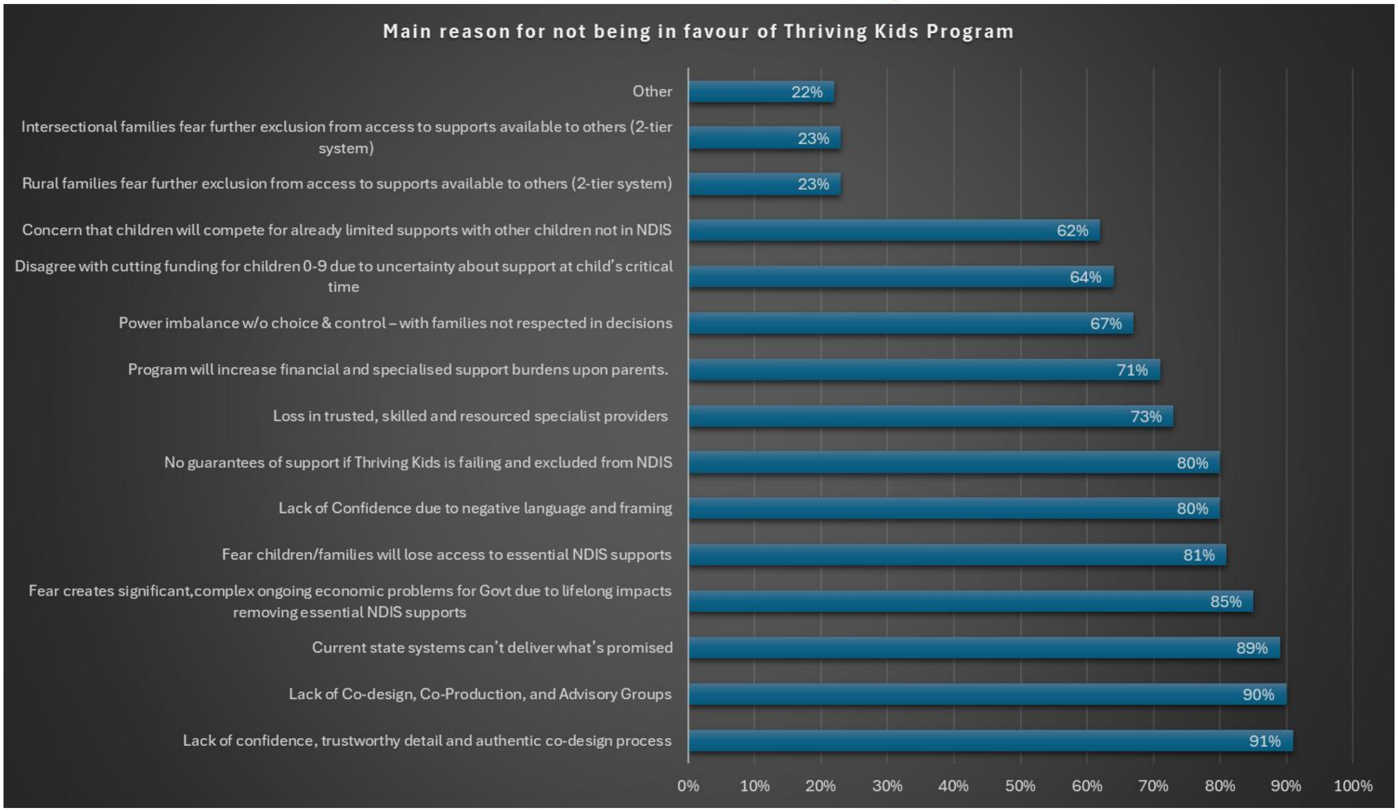
What are the immediate government opportunities for building trust and positive partnership?

These themes and opportunities (in the form of recommendations) have been addressed in Section 5 in response to the Parliamentary Inquiry Terms of Reference questions.

Note in Appendix 3 is the complete outline of the 15 Clear Government Steps to help build trust and move towards a constructive partnership in the timeframe.

5.3 Key concerns about the Thriving Kids program

The dominant reasons for not being in favour of the Thriving Kids program have been outlined in the table below with more detail of the key themes provided in Appendix 2. This sentiment was based upon the information available to respondents during September 2025 regarding the Thriving Kids program.



5.4 Key support about the Thriving Kids program

While the **9% mostly in favour did** not achieve statistical significance in this survey, we have included a reflection as it demonstrates what it is that people are aspiring to, and opportunities to build on.

4.3.1 Increased Access and Reduced Financial Burden

- Some respondents pointed to the opportunity for the Thriving Kids program to extend supports to children previously excluded from the NDIS, or to those who struggle with out-of-pocket service costs.
- There were those who agreed that the potential for "*no Medicare gap payments"* or more equitable, local access to supports and therapies was appealing, especially if it means that *"children who don't qualify for the NDIS would have clearer pathways to support".*

4.3.2 Simpler and More Integrated Systems

- Supporters stated that a well-integrated model, delivered through schools and local services, could reduce bureaucracy and be easier for families to navigate.
- There were those who agreed that Thriving Kids' vision of bringing *"health, education, and community supports into one system"* could streamline access and help make the NDIS sustainable for those with highest needs.

4.3.3 Early Intervention and Prevention Opportunities

- Some participants recognised the value in earlier developmental screening, coordinated support, and a mainstream system less rigidly tied to diagnosis.

4.3.4 Long-term Inclusion and Thriving for All

- A number of respondents hoped, if robust and authentically co-designed, that Thriving Kids could help advance broader community understanding of neurodivergence, reduce stigma, and build inclusion.

4.3.5 Cautious Optimism and Calls for Proper Implementation

- Almost all (the significant minority) who saw potential in the program concept emphasised that positive outcomes would depend on successful program design and implementation.

Appendix 2 also outlines the main themes regarding:

1. the impact of the Thriving Kids Program on the wider Autistic and autism community (negative impacts, positive impacts and uncertainty);
2. the three most important aspects of a Thriving Kids Program;
3. the three things respondents would hate to see in a Thriving Kids Program;
4. expectations for accessing services on the Thriving Kids Program that are not currently available on the NDIS.

The full survey convers many more areas and will be available end October 2025.

5. Addressing the Inquiry Terms of Reference

5.1 TOR 1: EXAMINE EVIDENCE-BASED INFORMATION AND RESOURCES

Terms of Reference 1: Examine evidence-based information and resources that could assist parents identify if their child has mild to moderate development delay and support parents to provide support to these children.

5.1.1 THE KEY THEMES AND FINDINGS FROM OUR SURVEY

Survey responses reveal a **lack of trust and a lack of confidence** in existing information, resources, and services. The key drivers are outlined below.

1. **Lack of Understanding of Autism, negative language and framing undermines confidence**

80% described the Government's language surrounding the Thriving Kids program as disrespectful, divisive, and gaslighting. Many warned that the Thriving Kids program was based upon an uninformed understanding of the Autism Spectrum.

> *"We need help to combat the offensive reporting on autism in the media (see the AFR, the Australian, sky news etc) and be armed to fight the autism wars. We need to push for standards for reporting/politicians/government making statements about disabilities and especially kids with disabilities".*

Respondents also criticised the lack of understanding of the autism's complexity and variability. They stressed that therapy should not be time-limited or based on assumptions that children will "graduate" from needing support.

> *"The messaging out low and high support etc is counterproductive and does not align with the National Autism Strategy".*
>
> *The Thriving Kids program raises significant concerns for families like ours, who are already navigating complex neurodivergent needs within under-resourced systems.*
>
> *The number of actual kids on NDIS is a problem but demonising autism not helpful.*

Autism - holistic and life-long

Autism is repeatedly grouped with "mild to moderate developmental delay". As reflected in the National Autism Strategy, autism is a **lifelong neurodevelopmental difference**. Autistic people share common characteristics that present **differently in each Autistic person**. Support needs may be **ongoing, fluctuating, and environmentally (context) dependent**.

Over 95% of Autistic people have a co-occurring disability and/or medical or mental health condition, and/or face multiple overlapping forms of disadvantage and discrimination due to intersectional identities. Without explicit protections and community co-production, broadly implemented and generic programs risk compounding inequity, where "families fall through the cracks" (see: Senate Inquiry on Autism report[1]).

Hence, while support needs vary, autism is not something that children "outgrow". For many, support is necessary throughout life. Whatever systems Autistic children and adults have access to need to consider the diversity of autism and take a holistic, individualised and total life approach.

> *"Autism is a lifelong permanent disability and think the language being used undermines this message to the community, and many co occurring conditions with autism that impact psychosocial functioning and mental health".*

Mild and Moderate

The terms "mild autism" and "moderate autism" are not recognised diagnostic categories in any current international clinical classification systems. Without standardised criteria, providers, schools, and government systems may apply "mild" and "moderate" differently, leading to inequitable outcomes.

Furthermore, the harm is that "Mild autism" is often interpreted as "not serious" or "not deserving of support," which can invalidate lived experiences and worsen inequities.

> *"See National Autism Strategy which was neuroaffirming and co-designed - but dividing through low/medium language is a step back"*

Evidence-Based

As reflected in the National Autism Strategy, the definition of evidence-based is comprised of three pillars:
1. Research evidence (science).
2. Clinical expertise (trauma-informed, culturally responsive, LGBTQIA+ inclusive).
3. Clients' values and preferences.

These pillars should be underpinned by lived experience and none of the pillars are to be valued higher than the other, they must all work together to be considered evidence based.

We also reference Autism CRC's Supporting Autistic Children Guidelines:

> *'Each child and family should be able to access the supports they need, when they need them, and in ways they desire, regardless of who they are, where they live, or how much money they have'* (recommendation 16, Autism CRC Supporting Autistic Children Guideline)

2. Parents need information they can understand and trust

91% of respondents were not in favour (60%) or undecided (31%) about Thriving Kids, primarily citing a lack of trustworthy detail, accessible information and an authentic co-design process. The

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[1]

contrast between the aspiration of assisting parents and the community experience of information provision is concerning as this goes to the heart of "assist parents" — if information is unclear, the program cannot succeed.

> *"There is no justification for why this is expected to work… it feels like a shot in the dark."*

> *"This is all very confusing and overwhelming, we are already at breaking point after a year of navigating the NDIS, I beg you to please make the information simple and accessible for us."*

3. Current information and service failures impact views

Respondents highlighted requirements through current system failures:

- Parents need information framed positively, not solely around "red flags" or deficits.
- Resources must balance awareness with reassurance, helping parents navigate confidently without being alarmed.
- Co-produced resources should be in plain language, culturally safe, and accessible (including translations).
- Honest overview of interventions is critical: many families are concerned about compliance-based approaches that prioritise "normalisation" over wellbeing.

> *Don't do this. It's a huge mistake, our children's mental and physical health will be negatively affected with devastating impacts on them and their families. It's against the UNCRPD to single them out for removal from the NDIS on multiple levels*

4. Parents need practical supports

Repeatedly cited were faster diagnosis, clearer pathways for children who don't meet NDIS thresholds, and access to no-gap allied health or Medicare-based options.

> *"Community supports delivered by people with knowledge and expertise of autism and DD. Timely, easy access for families. Ease of intersection with NDIS"*

> *"By denying diagnosis at the appropriate time, lives are being ruined and it's just compounding symptoms and pushing it down the line to other services".*

It should also be clear that Thriving Kids cannot rely on Medicare alone, or we will see a two-tiered system where only wealthier families can afford adequate care.

> *"Faster diagnosis, earlier access to early intervention services—NDIS is a very long process, meaning you miss half of the early intervention window before gaining access."*

> *"If the kids don't need a diagnosis but are identified as having needs…"*

> *Parents need better education."*

> *"It's creating fear. It's creating community divisions. It will create a tiered approach to care."*

5. Resounding call for Co-production and Co-design

Supported by best practice and the UN CRPD

"designed by autistic community, neurodiversity affirming practices, guided by autism CRC guidelines for best practice, client centred care"

> *Parents cannot assist their children without trustworthy, accessible, and co-produced resources. Thriving Kids will only succeed if it builds trust, restores lost practical supports, and ensures that families receive affirming, evidence-based guidance from the very first point of concern.*

6.2.1 RECOMMENDATIONS

Thriving Kids will only succeed if it builds trust, restores lost practical supports, and ensures that families receive affirming, evidence-based guidance from the very first point of contact. Without co-designed, neurodiversity-affirming information, families risk confusion, inequity, and delayed supports.

The recommendations below are informed by the survey and the Alliance's expertise and experience.

1. **Build trust through regular, transparent, and accessible grass-roots parent-facing information**, with evidence that before scaling a national support pathway materials used are co-designed and have been successfully piloted. Address communication themes found in the NAS consultation and principles of Universal Design in implementation.

2. **Reset towards co-production of practical supports** with Autistic people and autism community members as the primary recipients of the Thriving Kids program. Follow Autistic-affirming methodologies, aligned with the NAS, Roadmap and CRPD.

3. **Guarantee Early Identification and Referral – more in Appendix 5**
   a) Guarantee national access to validated screening and mandate training for GPs, maternal health nurses, and educators on developmental surveillance and autism-affirming practice.
   b) Mandate training for GPs, maternal health nurses, and educators on developmental surveillance and autism-affirming practice.

4. **Prioritise Parent and Families Empowerment**
   a) Fund autism-specific first steps programs that work alongside parents from the beginning
   b) Fund parent-mediated interventions that focus on communication, sensory regulation, and play.
   c) Reinstate and fund fully early pathway supports such as autism advisors, information helplines, and early-day workshops (refer ToR 2 response).

d) Ensure family supports by investing in navigators, peer supports & coaching/ mentoring, independent advocacy and respite. This includes prior to diagnosis and for Thriving Kids program transition so families do not carry the transition burden.
e) Invest in supports for siblings.

> *"…persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them" (UN, CRPD)*

5.2 TOR 2: EXAMINE EFFECTIVENESS OF CURRENT (AND PREVIOUS) PROGRAMS AND INITIATIVES

Terms of Reference 2: *Examine the effectiveness of current (and previous) programs and initiatives that identify children with development delay, autism or both, with mild to moderate support needs and support them and their families. This should focus on community and mainstream engagement, and include child and maternal health, primary care, allied health playgroups, early childhood education and care and schools.*

5.2.1 THE KEY THEMES AND FINDINGS FROM OUR SURVEY

Families have told us bluntly current systems are failing. Parents describe long waits, financial strain, and children pushed into mainstream settings that are already under-resourced and ill-equipped.

At the same time, families value early and integrated supports when they work. Models that do work remain rare and unevenly available. Families report a "postcode lottery."

> *"Potential to improve understanding of neurodiversity within schools, reducing pressure on children to comply with expectations that are not neurodevelopmentally appropriate…"*
>
> *"Hopefully Thriving Kids supports children to understand how they learn best, how to work with their strengths to be their best selves! I'm hoping there is suitable education on common ASD struggles such as anxiety and social skills."*

5.2.1.1 EFFECTIVENESS OF CURRENT AND PREVIOUS MODELS

1. **Pre NDIS: Patchy, inequitable, and fragmented, with widespread disparities in outcomes**

> *"The NDIS early intervention was created because pathways outside the NDIS did not work well in the past."*
>
> *"The NDIS review stated that block funding has not worked previously. This type of funding does not promote or give accessibility. How will the regions be supported?"*

There were some positives identified:

> *"Having experienced pre-NDIS serving & resourcing I found the public system less stressful to navigate there was greater integration with allied health and other government departments such as education and communities - it was child-focused - there was not the pressure of worrying about funding - reports - setting goals etc … it was straight up caring for my child."*
>
> *"Prior to the NDIS there were good examples of community supports available. Current parents may believe that prior to NDIS there was nothing, this is incorrect."*
>
> *"Early intervention for children is vital to put the supports in place EARLY to help them gain ground in the development space faster so they can have a better chance to succeed in school and life. I*

> *am very concerned that we will go back to the models of when my children were young 'of this child is it bad enough' to access any therapies yet."*

2. Post NDIS: System Failures and Local Inequity impacting views

After the introduction of the NDIS, the Select Committee on Autism found that while there had been some gains, the overall sentiment *of "**frustration with the siloed and fragmented nature of the support available for autistic people**"* (p.54) remained. The community attitude highlights the need for improvements to existing systems before introducing new ones. One respondent shares that the government:

> *"can't get one system correct and add(s) another (system) without any trial or consultation"*

The Select Committee on Autism found many stakeholders raising concerns about the *"compounding nature of inadequate support provision"* (p. 72), particularly in early childhood, which necessitates an increase in the need for services in other sectors. Ultimately, however, it is *"about actual support and not saving money"*: Foundational support forms the basis to build children's futures.

> *"Getting it wrong at this early age… steals their potential future - these mistakes will be borne by… children for the rest of their lives"*

While some initiatives have shown promise, effectiveness has been undermined by fragmentation, inequity, and under-resourcing. Survey comments reinforce this with key challenges identified as system failures, uneven resourcing and local inequities, with **89% in agreement that current state systems can't deliver what's promised** and that **it's a post code lottery.** Parents shared the difficulties of accessing local allied health services, including long wait times and inexperienced service providers.

> *"The current services that are state-funded are overwhelmed."*
>
> *"Children (are being) pushed to existing systems that currently aren't coping with referral load"*
>
> *“Families without an NDIS plan often locked out of mainstream services”.*

Furthermore, **77.7% of young Autistic people** face social, learning and communication difficulties at school (Select Committee on Autism, p.28). While many parents remain hopeful that schools could offer convenient therapy options, the statistics indicate that improvements are necessary before schools can be considered a viable site for service provision. Current systems are failing in practice. Survey comments from parents reinforce this point.

> *"I am concerned about moving therapies to group and early childhood settings, as they are inaccessible to my child. His main sensory triggers are noise and people - he cannot handle being in a classroom setting, let alone engage with therapy."*
>
> *“It could withdraw personal choice and control in therapy”.*
>
> *"Schools are appalling in their mistreatment and poor support of children with autism."*

While parents remained hopeful that schools could offer convenient therapy options, educators indicated that they were concerned of “*Difficulty integrating therapies into the school day without disrupting learning”*

3. Kids outside of the mainstream systems

Many survey respondents highlighted a lack of support for children who cannot attend mainstream early childhood settings or schools. Concerns included communication difficulties, mistreatment, trauma, bullying, sensory triggers, and *"school-can't".*

> *"My child was constantly sent home from school as his needs were not being met, and he wasn't coping. He is now unschooling from the trauma school provided. How would he access support?"*

4. Uneven Resourcing

89% of survey respondents say **that existing systems** (education, health, childcare) are **already under-resourced. Refer response under ToR4.**

> *"No support for children who live in smaller or remote locations"*

The minority of hopeful responses (9%) identify what might work: integrated delivery through early childhood services, no Medicare gap and earlier screening. At this stage, however, there is no evidence to suggest that all of these are inclusions to Thriving Kids.

> *“Providing more support through Medicare and in mainstream settings would be valuable especially for children who may have delays in one or two areas and are not diagnosed with global developmental delay…”.*

5. Training needed

Health and allied health practitioners *"often lack autism-specific training"* (Health and Mental Health Roadmap, p. 35). The National Autism Strategy and Roadmap recognise the importance of involving Autistic people in the delivery of comprehensive Autism-affirming training wherever possible.

> *It must allow for allied health access and individual neuroaffirming psychology supports too*

6. Rejection of harmful practices and lack of individualisation

Concerns about the risks associated with compliance-based interventions that are harmful are a recurring theme, and respondents stress the importance of neuro-affirming and personalised support.

> *“Current systems often rely on a "one-size-fits-all" approach, failing to address the unique needs of autistic children”*

> *“Group therapies and rigid programs lack flexibility and personalization”*

> *“Compliance-based approaches are harmful and stigmatising. We need neurodiversity-affirming practices that respect and celebrate Autistic traits”*

7. Market Structure – Avoiding Centralisation, Monopoly and Unregulated Providers.

There were a number of concerns raised about the resulting market structure including:

a) risk of large corporations or government-only services dominating the program, which could limit family choice. Local, community-based providers were preferred.
b) independent quality/ independent
c) unequitable access to high-quality supports, like long waitlists and socioeconomic disparities will result in families turning to unregulated providers.
d) one-size-fits-all approaches and cost-cutting measures that prioritise cheaper providers over quality services.

> *"Many of us have been NDIS participants for a number of years and know the failings of the system well. It has failed because the price guide made services inaccessible for people not on the NDIS."*

8. Transitioning too early

Dependent on respondent type there were different drivers of the challenges reinforcing the message that the current ecosystem is not ready and there is a lot of work to be done. This includes from professionals and educators:

- Difficulty coordinating services across sectors like education, health, and community services.
- Workforce shortages and high turnover rates.
- Lack of autism-specific and neurodiversity-affirming training
- Under-resourced schools lacking funding, training, and staff.
- Increased pressure on already overburdened teachers.

Parents are particularly concerned that Thriving Kids risks repeating past mistakes—removing children from the NDIS before mainstream systems are ready resulting in loss of individualised supports and trusted providers.

> *Kids already being exited from NDIS with no services available.*

> *“Doesn't recognise the potential long-term MH impacts for autistic kids if done poorly - just kicking the cost of support down the road.”*

5.2.1.2 SPECIFIC CURRENT AND PREVIOUS MODELS

5.2.1.2.1 Lessons from Pre and Post NDIS systems lessons

- State-funded programs like Help Children with Autism (HCWA) and autism advisors provided clearer, simpler pathways, but were underfunded and inconsistent across jurisdictions.
- Supported playgroups and block-funded NGOs offered baseline access but were limited in reach.
- Early Childhood Development Program, which was developed and delivered by state autism peak bodies, provided early years access with effective supports
- NDIS Early Childhood Approach had unprecedented funding and flexibility, but too complex for families with mild/moderate needs.
- A shift toward individualised plans eroded universal community supports.
- Educators are often the first to raise concerns but are ill equipped lacking training and resources.
- Family-Centered Support availability is of benefit such as:
  - parent coaching and coaching in ECEC settings have been proven to build skills and sustain outcomes. crisis support.
  - Provision of respite care and crisis support to reduce caregiver burnout.
  - siblings in support programs to address their needs.
- Transdisciplinary key worker model that is family-centred, and cross-agency empowers parents.
- Telehealth is effective for rural/remote families but must complement—not replace—face-to-face supports.
- A need for a clear baseline of numbers dealing with those who require support to avoid the reliance on state and government systems to identify how many people would need support going into the NDIS when first established.
- Integrated services (multi-D) - kindy, and family supports where intervention programs focus on neuro-affirming capacity building skills and confidence in stable learning environments that can be maintained. Independent evaluation shows significant developmental gains, reduced restrictive practices, and strong ROI.
- Government-run speech therapy, OT and physio programs noted for their effectiveness. In SA there was the Preschool Boost Program with therapy services linked to local government areas.

- Early Intervention through the Department of Education with impactful programs delivered without a billing agenda.

- Safe spaces for autistic children in schools to escape sensory overwhelm that follow universal design guidelines.

- Community Sporting Clubs that are supported to provide supportive environments where children thrive and feel included.

- Inclusive Community Sporting Programs: Helping children participate and thrive.

5.2.1.2.2 Elements or approaches that people would not like to see repeated

Programs or approaches that people would not like to see repeated include:

- **Compliance-focused methods**, that cause harm
- **Pathologising differences**, and pressuring Autistic children to mask or appear neurotypical.
- **One-Size-Fits-All Programs**: Generic approaches that fail to address individual needs and learning styles.
- **Forced Group Therapies/ Programs That Reduce Individualised Support**: Programs that mandate group settings without considering individual preferences or needs/ Initiatives that limit choice, control, or flexibility for families and participants.
- **Deficit-Based Models**: Approaches that focus on "fixing" autism rather than supporting neurodivergent strengths and needs.
- **Programs Run by Non-Autistic Leadership and /or Do not Include Neuro-affirming Practices**: Concerns about initiatives led by individuals or organisations without lived experience or lack expertise in neuro-affirming practices/ fail to respect neurodivergent identities and strengths.
- **Programs with High Bureaucratic Barriers**: Systems that create excessive red tape, paperwork, or hoops for families to access support.
- **Programs Delivered by Unqualified Providers**: Concerns about therapists or organisations lacking specific autism training or expertise.
- **Programs That Exclude Certain Diagnoses**: Exclusion of children with co-occurring conditions.
- **School-Based Therapy Only**: Concerns about excluding children who are homeschooled or unable to attend school due to sensory or social challenges.
- **Programs That Shift Responsibility to Parents**: Initiatives that place undue pressure on parents without providing adequate professional support.
- **Programs That Rely on Medicare Gap Payments**: Risk of creating inequities by making therapy unaffordable for low-income families.
- **Programs That Segregate Autistic Children**: Concerns about isolating children in separate programs rather than fostering inclusion
- **Avoiding Centralisation and Monopoly**: Concerns were raised about the risk of large corporations or government-only services dominating the program, which could limit family choice. Local, community-based providers were preferred.

5.2.2 RECOMMENDATIONS

The following recommendations are informed by the survey and the Alliance's expertise and experience.

Thriving Kids will only succeed if it avoids being another cost-cutting exercise and instead delivers what families actually need: accessible, affirming, and integrated supports from the start, with a total life cycle lens**.**

Above all, ensure supports are **individualised, neurodiversity-affirming, and co-designed** with Autistic people and families.

A current risk is that there are many children with developmental delay and mild and moderate support needs that are not on the NDIS, and their needs are not met. Once the Thriving Kids program is live, there will be competition for scarce resources.

Recommendations:

1. Baseline and Evaluate before reform

a) Comparative evaluations and pilot data from states and existing early-intervention programs completed before rolling out new program in readiness to transferring children from the NDIS.

b) Recommend the Committee request comparative evaluations/pilot data from states and existing mainstream early-intervention programs before any transfer of children out of the NDIS. Cite sector commentary noting the need for close federal-state co-operation.

2. Align with the National Autism Strategy First Action Plan commitment to review what already exists.

a) Enhance communication channels between federal and state governments in alignment with Commitment 20 (c) of the National Autism Strategy First Action Plan.

3. Define success and measure it

a) Develop an **outcomes framework** before rollout.

b) Anchor success in **Autism CRC guidelines** and **PRESCI best practice**: equal weighting of research, practice evidence, and family values.

c) Evidence is needed to demonstrate methods for the consistent and individualised implementation of supports in a mass-produced, cost-cutting environment

d) Baseline how many children are anticipating to access the Thriving Kids Program, working with all relevant stakeholders to develop the numbers (this includes NDIA, and National organisations and State/ Territory organisations).

4. Guarantee equitable access

1. Restore and expand universal supports: autism advisors, supported playgroups, key worker models, telehealth.
2. Guarantee access by removing out-of-pocket cost and gap payments.

Refer ToR4 regarding workforce

5. Fund collaboration between schools and therapists, and support children outside mainstream.

- Desire for interdisciplinary collaboration among therapists, educators, and families to ensure holistic support.
- Integration of therapy into natural environments, such as schools and homes

6. Strengthen mainstream services with Individualised and affirming approaches

1. No arbitrary therapy caps; intensity based on child’s assessed needs.
2. Ensure therapies are neurodiversity-affirming, strengths-based, and are relationship/ based and avoid harmful compliance practices/ Focus on therapies that build skills and confidence without forcing neurotypical norms.
3. Mandate autism-affirming training for GPs, child health nurses, allied health, and educators.

7. Ensure ethical and neuro-affirming practice

1. Require independent reviews of any intervention promoted through Thriving Kids.
2. Embed neurodiversity-affirming practices, aligning with the National Autism Strategy and UN CRPD.

8.Implement the Essential Principles for Reform as Preconditions and Evaluation Criteria – Appendix 4

5.3 TOR 3: EQUITY AND INTERSECTIONAL ISSUES

Terms of Reference 3: Identify equity and intersectional issues, in particular, children who identify as First Nations and culturally and linguistically diverse.

5.3.1 THE KEY THEMES AND FINDINGS FROM OUR SURVEY

1. Intersectional and Overlapping Vulnerabilities

The National Autism Strategy (NAS) recognises that *"policies and support services often fail to adequately support Autistic people who are members of…intersectional groups"* (p.11). Priority cohorts identified in the NAS, relevant to the Thriving Kids initiative, include children, First Nations Peoples, CALD and CARM communities, girls, gender-diverse individuals, and those with high dependency and support needs. The risk of disadvantage intensifies when multiple factors co-occur and/or socioeconomic or locational vulnerabilities are also present.

For Thriving Kids, this means equity cannot be treated as an afterthought. Children who identify as First Nations and culturally and linguistically diverse (CALD) face unique barriers that, if unaddressed, will deepen existing inequalities. As outlined above there are a number of other priority cohorts that need to be considered also.

Subtle or context-dependent presentations:

The survey provides explicit lived-experience testimony that intersectional and priority groups are at risk of under-diagnosis (due to masking and reliance on deficit-based models) or being "*syphoned off*" if milder categories are the focus. Many Respondents shared concerns that children with less obvious needs may be *"missed."*

"Young girls, gender diverse and people of colour are disproportionately affected by not being diagnosed or being diagnosed at lower levels because…they tend to be able to mask better and have higher social and emotional skills"

"A blanket model—especially one based on age or perceived severity—risks denying support to those who mask, diverge, or fall outside traditional diagnostic pathways"

Rural respondents described local service deserts and a lack of support, with local shortages in workforce and infrastructure, while intersectional respondents reported a higher risk of being excluded from both diagnosis and new foundational supports.

"…it will cause service to be even more of a "postcode lottery" with rural children missing out."

High dependency and support needs respondents described the challenge of being offered one-size-fits-all approaches when they require intensive and individualised therapy, lack of flexibility to adjust therapy intensity based on progress, changing needs, or crises. There was also the common theme of the lack of understanding regarding the need for family and caregiver support to reduce caregiver burnout and emotional toll on families and the inclusion of voices through supported decision making and/or from families and individuals in decision-making.

Respondents also expressed fears that therapy supports might be reduced or deemed "not worth the investment," due to the time for improvement to show and called for better understanding and investment in intensive, individualised interventions.

> *“A non-verbal child will need significant speech therapy intervention. If they don't get enough, results could be inconsequential. A child with severe introception difficulties may need intense OT and psychology to see gains and allow them a life free of pain, mental illness”.*

First Nations People experience:

1. **low diagnosis rates** and limited access to **culturally safe supports** despite experiencing developmental vulnerability at double the rate of non-Indigenous peers
2. **cultural and geographic barriers with** a paucity of relevant information, and significantly higher risks of poverty, transport, locational, cultural and language barriers, systemic discrimination (bias) creating additional barriers. With mainstream services often failing to reflect cultural values or community practices this increases their need for respectful and personalised programmes (Senate Inquiry on Autism report).
3. **limited co-design, with** families reporting inadequate representation and consultation with First Nations communities.

> *"My daughter is Aboriginal and there's very limited "Culturally Appropriate" supports currently in place, this is where individualised ndis plans have been amazing, it has allowed certain areas of support be developed and addressed without stigma or having to go without."*

Culturally and Linguistically Diverse (CALD)/ Culturally and Racially Marginalised (CARM) people experience:

- **language and cultural barriers with** many families identifying they cannot access translated resources, culturally informed screeners, or bilingual professionals. Standardised tools are often invalid in different cultural contexts.
- **systemic bias with** families reporting discrimination and rigid models that fail to respect and adapt to cultural values or parenting practices.
- **trust deficit with** past experiences of exclusion mean CALD/CARM families are less likely to engage with government programs unless meaningful community partnerships are built.
- **limited co-design, with** families reporting inadequate representation and consultation with CALD/CARM communities.

5.3.2 RECOMMENDATIONS

Without deliberate action acknowledging intersecting forms of disadvantage, Thriving Kids risks reproducing systemic inequities. Thriving Kids must embed equity binding safeguards to ensure inclusion is not aspirational but guaranteed, otherwise, the children who need it most will continue to miss out.

The following recommendations are informed by the survey and the Alliance's expertise and experience:

2. **Embed binding equity safeguards** to ensure children in marginalised groups are not left behind:
    - Undertake demographic-disaggregated **impact modelling:** require equity impact assessments (by Indigenous status, CALD, gender, rural/remote) and build binding equity safeguards into the design before implementation.
    - **Genuine Co-production** with intersectional groups to facilitate appropriateness and community acceptance (leaders, individuals, families, and organisations)
    - **Plan, fund and manage proactively (including iteratively)** the Thriving Kids rollout and implementation to prevent disadvantaging marginalised groups.
    - **Community advisory groups are resourced and embedded in governance**
    - **Anti-Discrimination Measures**: Implement safeguards to prevent systemic discrimination.
3. **Make Information, supports and Services Culturally Safe and Accessible**
    - Provide culturally appropriate information in multiple languages and fund interpreters.
    - Provide incentives for healthcare providers to work in remote areas.
    - Collaboration with First Nations and CALD Disability Representative Organisations to provide support and advocacy for families navigating the program.
4. **Workforce Development**
    - Invest in training, recruit and support First Nations and CALD professionals as part of workforce development. This includes the creation of scholarships and pathways for people from underrepresented communities (including Autistic people) to join the workforce.
    - Cultural and Equity Training Investment - Fund training in cultural competence, trauma informed and neurodiversity-affirming practice, with specific strategies for First Nations, CALD, LGBTQIA+, and rural/remote families.

5. **Invest in** culturally safe **Place-Based and Flexible Support Delivery Models**
    - Fund community hubs and outreach programs including in remote areas, employing First Nations/ CALD staff as cultural liaisons.
    - Avoid “one size fits all” designs—meet families where they are with culturally relevant approaches.
6. **Accountability and Transparency**

- Require all Thriving Kids programs to demonstrate how they will reach and serve marginalised groups and monitor outcomes.

"In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration." (CRC, Article 3)

5.4 TOR 4: GAPS IN WORKFORCE SUPPORT AND TRAINING

Terms of Reference 4: Identify gaps in workforce support and training required to deliver Thriving Kids.

5.4.1 THE KEY THEMES AND FINDINGS FROM OUR SURVEY

The Select Senate Committee on Autism, National Autism Strategy (NAS), and National Health and Mental Health Roadmap on autism agree that workforce shortages and the need to strengthen understanding and capabilities in autism and neuro-affirming practices are significant barriers to service delivery.

The majority of the 81 recommendations in the Senate Select Committee on Autism report[2] found that the biggest barrier to inclusion is lack of autism knowledge, skills and confidence.

As the Alliance responded in its NDIS Review submission the array of systems at all levels in the ecosystem undoubtedly are willing to do better – but do not know how.

The survey results had similar themes. Autistic people, parents, educators service providers, and community stakeholders all raised concerns about the readiness to implement a Thriving Kids Program on a faulty basis given the depth of workforce shortages, the lack of and patchy autism-specific and neuro-affirming training, and the absence of a coordinated national workforce strategy.

In fact, 73% of respondents are deeply concerned that there aren't "trusted, skilled and resourced specialist providers" are critical to hope and chances for a successful progression through childhood and beyond. They emphasise the importance of individualised supports, workforce quality and service continuity.

1. Implementing faulty broad scale solutions

In its initial action plan, the NAS aims to **define best practices and training** in care across service settings and develop outcome measures in collaboration with Autistic people and the autism community. Without first completing these actions as a critical component of the Thriving Kids program, there is a high risk of implementing faulty, broad-scale solutions that will be difficult to rectify, are not sustainable and put children at risk who need continuity of specialist skills.

> *“This should have been done in parallel with the autism strategy rollout for cohesive service provision.”*

> *“Avoid reliance on unqualified or undertrained staff, such as allied health assistants or general educators”*

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[2] Senate Select Committee on Autism, Parliament of Australia, Services, support and life outcomes for autistic Australians (2022) [vi-vii]

2. Workforce Shortages and Gaps in Trusted, Skilled, Integrated and Resourced Specialists

Individualised, neuro-affirming support is a niche skill. A skilled, sustainable, and supported workforce is critical for the success of Thriving Kids.

Survey responses highlighted:

- **Specialist Workforce Shortages:** Severe shortages of speech pathologists, occupational therapists, psychologists, and allied health professionals, particularly in public health, regional, and remote areas.
- **Inconsistent Training and Capability with** many educators, GPs, and early childhood professionals lack autism-specific and neuro-affirming training. Skills such as trauma-informed practice, cultural safety, developmental surveillance, and inclusive classroom strategies are inconsistent across the workforce.
- **Lack of Integrated, Multidisciplinary Training with** professionals often working in silos. Families fall through cracks due to poor collaboration across health, education, and disability systems.

"Our children need to be comfortable with the therapists they work with… I think it will destroy the self-esteem and identities of (an) entire generation of Autistic children."

"I don't think the government have actually thought about the impact of the relationships our children have with their therapists who form part of their circle of security."

From a professional perspective:

"…mainstream and public health services are not sufficient in providing what these children need. Support needs can fluctuate over time depending on age, life circumstances, degree of informal supports, and the impact of co-occurring disabilities and health conditions."

"Difficult access. Long wait times. Staffed with all new graduate therapists because experienced therapists don't want to take a pay cut to work for the State"

"Community programs and services often lack the skill set to deliver effective autism-specific support".

"You can't just fill jobs with anyone."

3. Retention, Burnout, and Workforce Readiness

Survey responses identified that the sector risks implementing services before workforce readiness is achieved, leaving families without support during transition. Other risks were burnout and turnover due to high caseloads, poor pay, and administrative burdens.

> *Professionals face unrealistic work expectations and lack neuro-affirming practices and education.*
>
> *Mainstream schools are struggling to cater to neurodivergent children due to underfunding and limited capacity*

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*Ultimately, **workforce quality and quantity is not optional** – without it, Thriving Kids cannot be sustained. That would leave children worse off*

5.4.2 RECOMMENDATIONS

The following recommendations are informed by the survey and the Alliance's expertise and experience:

1. **Plan and Pilot First: Recommend a pause to Thriving Kids** until Autistic-affirming best practices in training in care are clearly defined with outcome measures through the NAS.
2. **Develop a National Workforce Development Strategy including a capacity audit competency framework and funded training plan**
   f) **Create a national workforce plan** with training subsidies, rural incentives, and specialist recognition and **National Competency Framework**
   g) Develop a tiered competency framework (building on UK models) to ensure all staff, from GPs to specialist clinicians, are trained in autism and neurodiversity-affirming practice (different tiers dependent on level of interaction) and promote neurodiversity.
   h) Require a national workforce capacity audit and implement a funded training plan before any large-scale transfer of services.
      - Invest, attract, retain and support through scholarships, workforce incentives, retention and support measures (clearer career pathways, better pay, reduced admin load, improve well-being). Include incentives to ensure attract and retain to community-based and regional roles
      - **Expand workforce capacity through Lived Experience Representation**: invest, attract and retain neurodivergent professionals and lived experience. Include neurodivergent and lived experience in into training programs.

   i) **Develop Multidisciplinary and Community-Based Models**

- Promote co-location of services in health, education, and community services.
- Provide cross-sector collaboration skills training to improve coordination across sectors (e.g., health, education, community services) and engage Autistic people and families in delivery.
- Develop navigator roles to help families transition smoothly between services.

j) **Protect Specialist Expertise**

- Safeguard autism-specialist roles (speech, OT, psychology) within transdisciplinary models to prevent dilution of expertise.
- Ensure supervision frameworks and graduate pipelines to grow sustainable specialist capacity.
- Train in Evidence-Based and Individualised Approaches

5.5 TOR 5: DRAWING ON DOMESTIC AND INTERNATIONAL POLICY EXPERIENCE AND BEST PRACTICE

Terms of Reference 5: Draw on domestic and international policy experience and best practice.

5.5.1 THE KEY THEMES AND FINDINGS FROM OUR SURVEY

1. Lack of alignment with Existing Strategies and Best Practice

The survey feedback underlined a lack of alignment with existing strategies and best practice:

> *“Fair, transparent and ethical. Needs to place well being of the child first. Must align with UNCRC & UNCRPD. Must be culturally respectful (including disability culture). Should not be decisive”.*

> *Undermines the Government's commitment to support Autistic people outlined in the National Autism Strategy and Roadmap. Thriving Kids should have been aligned more strongly to the National Autism Strategy, or it should have been announced under the Strategy and its guiding Principles*

> *This policy, needs to align with the National Autism Strategy to realise the goal if the strategy to improve life outcomes for autistic people and to improve community awareness and challenge bias and stigma.*

2. **Best Practice Co-Production:** Although government material mentions expert advisory groups, the survey clearly shows that co-design based on lived experience has been lacking. Respondents request evidence of co-design and strongly call for:

> *“Autistic co-production and transparency over the next two years before rollout”*

3. **Advisory Group composition:** The recently announced Advisory Group is primarily expert-based and lacks lived-experience participants, relying on an outdated consultation model rather than best practice co-production. This is evidenced in its inaugural Communique, asserting that submissions are sufficient as *“...an avenue for a broad range of stakeholders and those with lived experience to inform the design.”*

> *“Families deserve transparency, co-design, and a system built on trust—not assumptions”*

4. **Staged Pilots and Independent Evaluation:**

> *“………Without longitudinal data, independent evaluation, or clear co-design with neurodivergent families, it is premature and irresponsible …”*

> *"A smaller trial for a few years to show that it can work. Information on how much support will be funded and in what areas. Information on how this will be different to pre-NDIS times. Open access to documents in consultation with lived experience autistic people and lived experience clinicians"*

5. Needs-based supports instead of diagnostic-based supports:

Article 26 of the CRPD states that services and programmes should *"Begin at the earliest possible stage and are based on the multidisciplinary assessment of individual needs and strengths."*

The survey shows broad agreement, with **94% rejecting outdated labels** in favour of basing supports on individual needs.

> *"Every child is different and needs different supports depending on their circumstance. You can't just throw a child into a generic program and expect that it will suit all children with needs"*

OVERSERVICING

To the question of best practice, it has been indicated that many of those children in the NDIS are being over-serviced with 80 sessions being too much.

The main themes and percentages by respondent type to the question are as follows:

- **54%**: believe therapy intensity should depend on the child's individual needs.
- **41%**: disagreed that "80" sessions are excessive
- **5%** agreed 80 sessions are "too much."

The overarching theme is the importance of individualised, goal-oriented approaches rather than arbitrary limits. Across all respondent types, therapy goals are emphasised as individualised, measurable, outcome-oriented, and collaborative, with a focus on practicality and respect for the child's unique needs and identity.

This is consistent with the Autism CRC Supporting Autistic Children Guidelines that indicate:

> *'Each child and family should be able to access the supports they need, when they need them, and in ways they desire, regardless of who they are, where they live, or how much money they have'* (recommendation 16, Autism CRC Supporting Autistic Children Guideline)

5.5.2 DRAWING ON DOMESTIC AND INTERNATIONAL POLICY EXPERIENCE AND BEST PRACTICE

Autism CRC Guidelines and the National Best Practice Framework for Early Childhood Intervention (ECI) provide a blueprint for strengths-based, family-centred, culturally respectful support in natural settings (home, preschool, school).

NDIS Review (Foundational Supports) highlighted the need for universal, needs-based supports available to all children, regardless of diagnostic label, with a pathway to specialist services as required.

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability found underfunded mainstream systems perpetuate segregation and exclusion — reforms must strengthen universal inclusion.

The National Autism Strategy, National Health and Mental Health Roadmap and UN human rights instruments all emphasise respect for self-determination and autonomy, including co-design, thorough evaluation, and the adoption of universal design principles.

Best practice is defined in the context of the National Autism Strategy (NAS) as:

- Strengths-based, trauma-informed and neurodiversity affirming.
- Embracing safety, choice, collaboration, empowerment, and respect for diversity.
- Co-leadership between government and the Autistic and autism community.
- Informed and guided by lived experience, expertise and insights.
- Evidence-based decision making (see definition of evidence based).
- Data-driven, outcomes focused, with robust monitoring and evaluation.
- Culturally safe.
- Includes people with diverse support needs, including those with very high support needs, and their families and carers.

Best practice in early childhood support is defined by three recurring themes across domestic reviews, international frameworks, and community feedback:

- Rights-based, neurodiversity-affirming approaches consistent with the UNCRC and CRPD.
- Co-design with lived experience, not token consultation.
- Evidence based - research/ evidence in practice and individua;/ family values and preferences) + independent evaluation, including transparency on outcomes, risks, and unintended effects.

International Best Practice

- **Canada**: National autism framework (federal principles + provincial delivery). Ontario's caregiver-mediated early years program expands access while retaining specialist pathways. *Lesson: national standards + local delivery + caregiver partnership.*
- **Scotland**: 10-year autism strategy with measurable KPIs and independent evaluation achieved system-level improvements. *Lesson: long horizon + accountability + evaluation = sustained progress.*
- **Ireland & Italy**: Universal inclusive education and early years inclusion laws embed children with disability in mainstream classrooms with tailored supports. *Lesson: inclusion from the start is feasible and beneficial.*
- **New Zealand**: Mobile early intervention teams work alongside educators and parents in natural settings, emphasising capacity building rather than extraction.
- **WHO Caregiver Skills Training (CST)**: A globally tested, scalable, low-resource model using non-specialists, with positive results for family wellbeing and child development.
- **UK**: Utilised the tiered National Competency Framework

Three key lessons from domestic and international best practice:

1. **Co-design is non-negotiable** — every successful reform (Canada, Scotland, Autism CRC) embedded lived experience at its core. Current advisory structures fall short.
2. **Pilot, evaluate, then scale** — international evidence (Scotland, WHO CST, New Zealand) shows long-term gains only come with staged pilots, independent evaluation, and transparent reporting.
3. **Needs-based, inclusive systems work best** — the CRPD, Autism CRC, and the NDIS Review are clear: supports should be built around children's individual needs, not outdated diagnostic labels, and delivered in everyday environments like schools and childcare - ensure this is directed and becomes part of guiding principles.

5.5.3 RECOMMENDATIONS

The following recommendations are informed by the survey and the Alliance's expertise and experience:

2. **Review, Evaluate and adopt domestic and international lessons:**
    a. **Systematic review** of international literature and Australian pilots.
        - Federated governance (national standards, local delivery tied to KPIs).

  - Caregiver-mediated, school-partnered approaches to expand reach.
  - Long-term, cross-government strategies with evaluation cycles (e.g., Scotland).
  - Knowledge translation hub to synthesise learnings from domestic pilots and international frameworks.

b. **Seek comparative evidence on**: (a) successful integrated early-support models internationally, (b) transitions off disability schemes and safeguards used elsewhere, and (c) evaluation frameworks showing no net loss of support for vulnerable children.

c. **Plan the shift towards needs-based right based framework of supports (align with CRPD Article 26)** instead of diagnosis-based ones.

3. **Mandate neurodiversity-affirming standards**: ban harmful mandatory practices and require conflict-free evidence reviews (disclose COI).

4. **Time Required for Improvement**: Respondents emphasized that children may take time to show progress or capacity building, and therapy should not be prematurely withdrawn based on short-term results.

5. **Co-design and governance**
   a. Establish paid, representative co-design panels (autistic people, families, priority groups in NAS
   b. Reform advisory structures to include lived-experience-led models, rather than just expert-led.
   c. Establish interfaces with existing groups - the National Autism Strategy Implementation Advisory group and the NDIA Autism Advisory Group and NDIA Children and Young People Reference group, NDIS CEAG
6. **Staged Pilots, Independent Evaluation and Public Reporting**
   a. Require staged pilots in diverse locations (including rural/remote and priority cohorts). Ensure public independent evaluation and real-time feedback mechanisms; publish pilot criteria and metrics in advance.
   b. Independent ethics-approved evaluation with adverse-effects monitoring and no program scaled nationally until safety and effectiveness are validated.
   c. Publish public dashboards showing equity metrics, access times, and workforce distribution.

7. Development of Guiding Principles

Refer Appendix 4 for the detail.

To get this right, we call for government to adopt 11 essential principles as preconditions and evaluation criteria for Thriving Kids rollout.

1. Co-produced from the Start
2. No-gap protections guarantee
3. Pilot, evaluate, scale — in that order.
4. Human-Rights Anchored, Neuro-Affirming Standards
5. Fit-for-Person Life-Span Approach in a universal system.
6. Competent Autism Specialists in a Mainstream Environment
7. Transparency and Accountability
8. Long-Term Outcome Evaluation
9. Cross-government Shared Accountability (Federated Governance)
10. Build on What Exists
11. No Go if Not Ready Safeguard

5.6 ToR 6: IDENTIFY MECHANISMS THAT ALLOW A SEAMLESS TRANSITION

Terms of Reference 6: Identify mechanisms that would allow a seamless transition through mainstream systems for all children with mild to moderate support needs

5.6.1 THE KEY THEMES AND FINDINGS FROM OUR SURVEY

1. Who is the system being designed for?

When ensuring a smooth transition and to achieve the program outcomes, it is essential first to consider whose needs the system is designed to serve.

On this basis while we understand that Government has decided that certain children are to be serviced by Thriving Kids Program.

Notwithstanding, the Thriving Kids Program announcement recognised that all children are precious. So given at the heart of who this system is being designed for is children, Thriving Kids should employ a Universal Design approach to allow flexibility for the adaptation of the evolving needs of the child, their individual circumstances and family contexts. This ensures that the process is not only fit for purpose but fit for person (individualised). These needs can be most effectively identified and addressed through collaborative co-production based on lived experience.

“If our society (schools included) were better equipped to support disabled people, they wouldn't need so much support to exist in society.”

> *“If done well, it will be a fully integrated system that will provide great benefits for every Autistic child.”*
>
> *“I like the idea of my child receiving support in the school day which will make our lives less complex.”*

2.Chaotic and Inconsistent Transition - many drivers to balance

The survey responses convey a dominant apprehension about the risk of a chaotic and inconsistent transition. Respondents fear losing NDIS supports; shifting costs to families; increased mental-health and education needs later; and administrative gaps where *"mainstream says it's disability, (but) NDIS says it's health.”*

"There is no justification for why this is expected to work. There has been no trial. It feels like a shot in the dark, which means there will be issues, and it may fail. Yet the kids are the ones whose whole lives will be impacted when it does

"It could destroy my children. It has taken long enough to get supports into place already, and now that they are finally building rapport and starting to make gains, the changes, transitions, and instability could be disastrous."

"Children are at critical developmental stages of their life – disruption is not an option"

Transition periods are especially challenging for Autistic people, and getting it right is crucial to prevent long-term barriers (Health and Mental Health Roadmap).

Systems should be well-prepared, coordinated, and resourced to address transition needs with flexible, multi-pathway approaches (see: Senate Inquiry on Autism report). Children should be supported at every stage, from entry to exit, to prepare them for smoother futures; otherwise, the government is merely *"kicking the cost down the road."*

> There are "multiple ways of learning a curriculum and not a cookie-cutter approach.
> No autistic child learns the same. But they all can learn."

"As a professional who will have the burden placed on me, as a teacher with… under-resourcing and no funding available or skill levels, as a parent of neurodiverse children who will be severely impacted, and as an autistic person, I am appalled by this."

Transitions for autistic kids are already hard. If we get them wrong, we are not saving money — we're ***just creating a greater societal cost*** *into mental health crises, disengagement, and family breakdown.*

There is no justification for why this is expected to work. There has been no trial. It feels like a shot in the dark, which means there will be issues, and it may fail. Yet the kids are the ones whose whole lives will be impacted when it does"

5.6.2 RECOMMENDATIONS

The following recommendations are informed by the survey and the Alliance's expertise and experience.

5.6.2 Recommendations

The following recommendations are informed by the survey findings and the Alliance's expertise and experience.

1. **Develop a Whole-of-System Reform Roadmap**
   Develop a clear roadmap for whole-of-system reform across education, health, and community services. The focus must be on fixing systemic gaps, not shifting children into systems that are already failing them.

2. **Implement a Vertical and Horizontal Integration Accountability Transition Plan**
   (Refer Appendix 5)
   This plan must include:
   - **Individual transition plans** demonstrating how each existing NDIS-funded support will be matched or bettered under the Thriving Kids model, with measurable KPIs and timelines.
   - **Concrete transition guarantees**, including:
     a. No child is off-ramped until a verified and operational alternative is in place
     b. Statutory entitlements to continuity of care
     c. Formal dispute-resolution and appeal pathways
     d. Guaranteed funding continuity for families during transition
   - **Education-specific transition supports**, including documented transition objectives in the year of change and follow-up written plans for teachers.
   - **Clear accountability levers** at three levels:
     - Federal cross-portfolio level
     - State/Territory and local system level
     - Individual child level

   As families and professionals consistently warned: to go fast is to go slow.

3. **Establish Formal Safeguards During Transition**
   - Formal government-led dispute resolution and complaints mechanisms
   - Guaranteed funding continuity so families are not left in limbo
   - Legislative “no-gap protections” ensuring no child loses support before validated alternatives are in place

4. **Introduce a System “Superhighway” With On- and Off-Ramps**
   - A National Neurodevelopmental Superhighway, where the Early Diagnosis and Access Pathway establishes a nationally consistent, neurodiversity-affirming framework ensuring that every child or young person can be identified early, assessed promptly, and supported continuously, without financial or systemic barriers. The pathway operates as a “neurodevelopmental superhighway” with multiple entry and exit ramps and clearly sign-posted doors to the right level of support. Refer Appendix 6 for more detail including diagram.
   - Develop a shared **profile passport system**—similar to hospital passports or reasonable adjustment passports—so families do not have to repeatedly “start over” at every transition point, including transitions in and out of the NDIS.

5. Develop Guiding Principles for Transition

- Transitions should be governed by principles of:
    - Neurodiversity-affirming, strength-based practice
    - Universal design
    - Shared accountability across systems
    - Genuine co-production with children and families

Refer Appendix 4 “Our 11 Essential Principles for Reform”

6. Establish Developmental Hubs

- Create developmental hubs that integrate services and align with ToR 4, supporting workforce training, collaboration, and shared accountability.

8. Mandate Workforce Training

- Require mandatory training for educators and mainstream service providers in autism, neurodiversity, and inclusive practice.

9. Fund Family Navigators and Lived-Experience Advocates

- Invest in family navigators, advocates, and lived-experience liaisons at every major transition point. These roles should provide navigation support, advocacy, peer mentoring, and respite, ensuring families are not left to shoulder the burden alone. Navigators and supports must be trusted, culturally responsive, trauma-informed, and deeply connected to community.
- The Alliance strongly recommends that local navigation be recognised as an essential component of the Thriving Kids initiative—not an optional extra.
- Survey participants were unequivocal: families and Autistic individuals are exhausted by fragmented systems. Navigators were identified as a practical, immediate solution to reduce stress, burnout, and disengagement during transition.

9. Build on What Already Works

- Reform must build on, not duplicate, evidence-based models that are already effective.
- For instance, independent disability advocates already exist who meet national standards and possess the infrastructure, knowledge, and expertise to build capacity and train others. It would be a natural extension for these advocates to take on the role of safe concierges and conduits, providing trusted support within the system

10. Strengthen Independent Autism Advocacy

- Independent, specialised autism advocacy services—particularly for marginalised groups including regional communities, culturally diverse families, and those with high support needs—must be embedded and funded. Existing advocacy organisations already meet national standards and have the expertise to act as trusted concierges within the system.

11. Simplify Processes and Increase Transparency

- Reduce bureaucracy and administrative burden for families
- Implement public reporting on transition outcomes and system performance

12. Ensure Continuity Across Life Stages

- Develop a Stage 2 roadmap that ensures continuity across key life stages, including school entry, transitions between grades, and post-school pathways.

13. Monitor and Enforce Outcomes

To go fast is to go slow

> *"There is no justification for why this is expected to work. There has been no trial. It feels like a shot in the dark, which means there will be issues, and it may fail. Yet the kids are the ones whose whole lives will be impacted when it does"*

6 Moving Forward

The Australian Autism Alliance calls on this vitally important Parliamentary Inquiry into the Thriving Kids program to implement the identified recommendation to safeguard Australia's Autistic people and autism community to ensure no Autistic child is left behind.

The recommendations are prudent, considered and provide a practical way to move forward so progress can be made in a staged way.

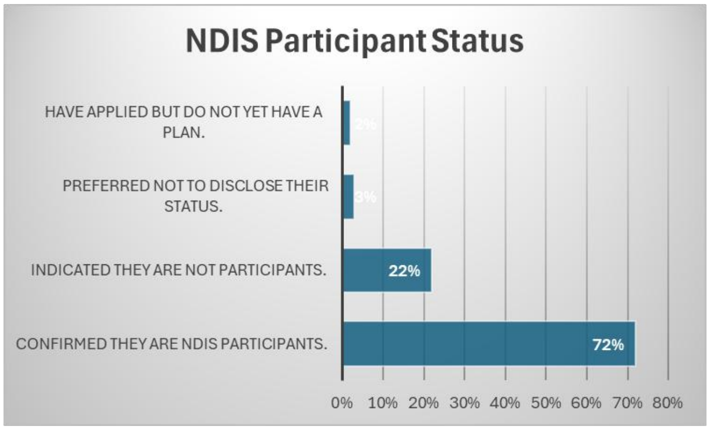
A pause to plan, plan and plan involving progressive actions and decision gates plus a genuine codesign is prudent.

Appendix 1: Snapshot of Thriving Kids Program Community Pulse Survey Respondents Profile

Below is a summary of the respondent profile. A final report of the survey results will be provided to the Parliamentary Inquiry with further analysis and information at the end of October 2025.

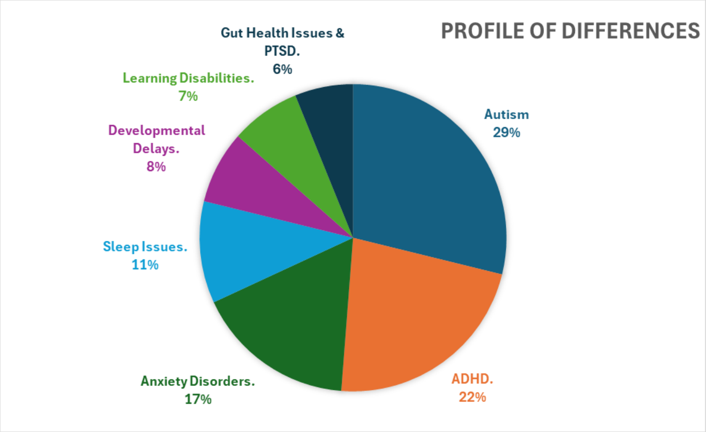
1. NDIS Participation Status

The majority of respondents are participants in the NDIS program.

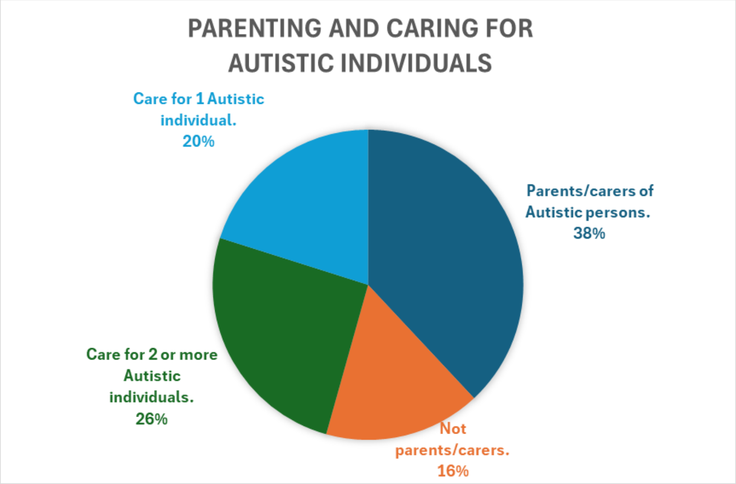


2. Conditions and Disabilities Reported

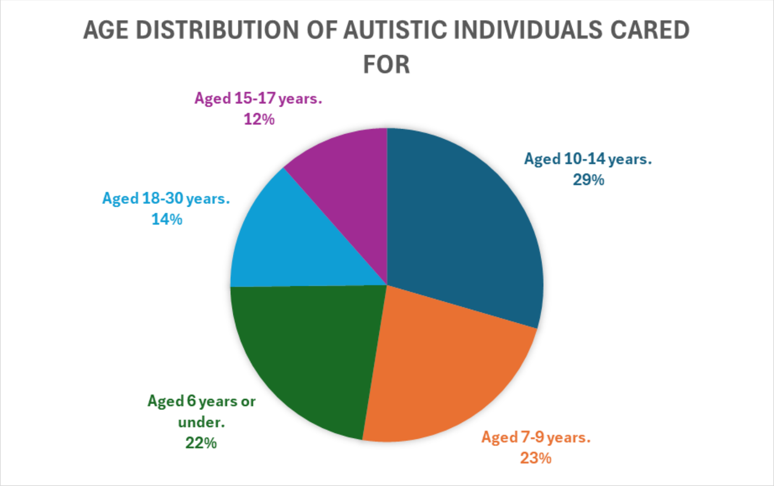
A wide range of conditions and disabilities are reported among respondents and those they support.



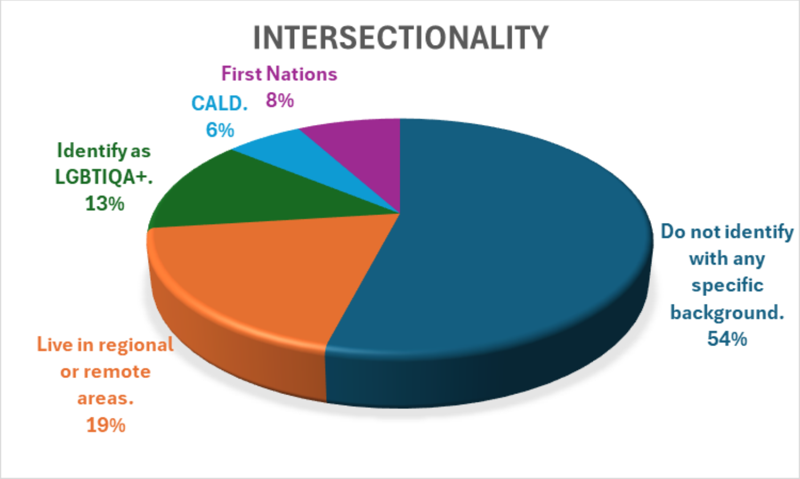
3. Parenting and Caring for Autistic Individuals



4. Age Distribution of Autistic Individuals Cared For



5. Identification with Diverse Backgrounds



Appendix 2: Snapshot of Thriving Kids Program Community Pulse Survey Results

During September 2025, the Australian Autism Alliance invited Autistic people and the autism community to share their opinions of, and suggestions for, the Thriving Kids program. This was prior to the Parliamentary Inquiry being released.

Note *the below results are subject to change once the more detailed analysis occurs.*

The findings from this most topical survey of community opinions and suggestions have informed this submission.

2.1 OVERALL SENTIMENT

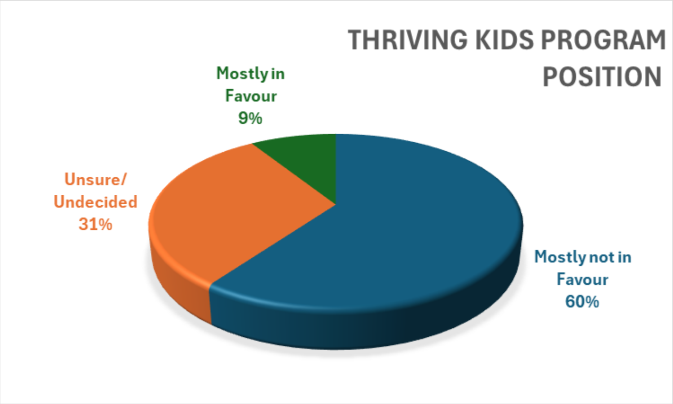
At the time of writing this submission, our survey had drawn 429 responses in just two weeks. Our survey, which was responded to by Autistic people, families, and allies nationwide, revealed overwhelming concern and a critical lack of trust in the Thriving Kids program. The majority of respondents **(91%) were mostly not in favour** of the program **or were undecided about it** (due to the lack of accessible information available). Nine percent were mostly in favour of the program. The Alliance's survey also collected the rationale for their opinions.

Autistic people and the autism community's anxiety and distress are palpable.

"We are worried. We are tired. That's all."

"I fear for what the future looks like."

"We've been promised the world too many times. Hope is only a flicker we reserve for our children……..."



Families told us bluntly that they fear this transition will be chaotic and damaging.

"It could destroy my children. After years of building rapport and progress, instability could be disastrous."

Our community is clear: Reform is needed. But not like this. At the time of writing this submission Australian Autistic and Autism Community Voices are calling for the Government to reset by pausing Thriving Kids until it is rebuilt on the right foundations.

The response was also united in its demand for transparent, equitable, and genuinely co-designed reform of the NDIS and localised Foundational Supports.

Of the **9% mostly in favour** of the program almost all who saw potential in the program concept emphasised that positive outcomes would depend on successful program design and implementation, adequate funding and genuine co-design in partnership with individuals and families with lived experience of autism.

2.2 KEY CONCERNS ABOUT THE THRIVING KIDS PROGRAM

The dominant themes for not being in favour of the Thriving Kids program have been outlined below. This sentiment was based upon the information available to respondents during September 2025 regarding the Thriving Kids program.

2.2.1 Overall: Lack of Confidence, Trustworthy Transparency and Co-design

- **91%** are not in favour of the Thriving Kids program or are undecided, primarily citing a lack of confidence, trustworthy detail and an authentic co-design process. This has escalated community stressors and caused additional angst within a vulnerable community of Australian citizens.

> *"The announcement alone has had a negative impact on the autistic community. The sudden announcement, the incorrect and ableist language, the lack of consultation with autistic people… have all been extremely stressful."*

Many comments reflect feelings of exclusion among Autistic people and the autism community:

> *"If anyone with Autism was consulted at any stage, surely they would know that Autistic parents would react with uncertainty over such a vague and threatening announcement? " We are being asked to trust that you will do right by our community, while being excluded from the planning and development of a program that directly affects our lives. "*

> *"Those in charge have openly acknowledged their lack of lived experience and unfamiliarity with appropriate language. This is not a minor oversight—it is a fundamental flaw in the foundation of any program claiming to support neurodivergent children. "*

2.2.2 Lack of Co-design, Co-Production, and Advisory Groups

- **90%** of respondents indicate that they do not feel that the government has demonstrated meaningful co-design with Autistic people, their families or the autism community in relation to the Thriving Kids program. Many respondents made reference to the National Autism Strategy as it outlines its commitment to including Autistic people, their families, carers and autism professionals in all issues that impact them.

"You have an opportunity to build trust back with the autistic community. Please don't ask for our opinions if there is no intent to listen or do anything different. We already don't trust you; we will further not trust you."

"The government has not demonstrated meaningful co-design with Autistic people, their families or the autism community."

"Nothing about us, without us. The community has not been involved."

2.2.3 Can't Deliver as Reliance on a Foundation of System Failures

- **89%** say current state systems can't deliver what's promised; many share stories of system failure and their experiences drive additional fears of forced change.

  "Atm it's just creating fear and anxiety. It is minimising their disability, putting them into boxes."

  "Just know that so many parents are angry and fed up. I'm one of many. I just want my son to have his voice back… we've been promised the world too many times, hope is only a flicker we reserve for our children. Not for grand schemes and pipe dreams like his."

  "…….We need more information on what services would still be available to our kids. Mainstream schools are struggling as it is. They do not have the funding or resources to have adequate support……."

- In addition, 85% say reform must start with Autistic lived experience and the piloting of new programs, prior to the removal of NDIS supports.

2.2.4 Risks of Loss and Harm with ongoing economic problems for Australian Governments

- **80%** fear that there are no guarantees of support if Thriving Kids is failing and excluded from NDIS

  Our community continues to call for programs that truly uphold rights and identity.

  "We are hurt and angered. We feel isolated and discriminated against. It feels like the govt don't want us anywhere and are not serious about early supports to reduce harm to the autistic community later in life."

- **81%** fear children and families will lose access to essential NDIS supports (promised by Australia's NDIS) and this will create increased reliance on other systems. e.g. increased health and education support needs for Autistic children, reduced employment outcomes leading to increased reliance upon social supports in their adulthood. We have also received notifications of significant worries and concerns within the Autism community relating to the design and implementation of generic, top-down models:

  "It will decrease access to individualised funded supports. It will lead to reducing the NDIS back to a block funded institutionalised based program that was in existence pre-NDIS."

  85% fear this will create significant, complex and ongoing economic problems for Australian Governments, due to the lifelong impacts of their removal. Many fear a mental health crisis for families and economic strain with out-of-pocket costs, reduced workforce participation, perpetuating cycle of poverty and social exclusion. The lack of respite care and family-centered support adds to emotional and financial strain. Increased pressure on other underfunded systems, such as education, healthcare, and social services, potentially leading to systemic failures.

.

“Parents with Autistic children are already managing extreme layers of stress and anxiety with their children and their additional needs for supports. The proposals are only adding to this stress and worry… Carer burnout is real, and this adds to the risk.”

“The other issue is with developmental delay, sometimes disability and health issues overlap. The problem then becomes NDIS saying it's a health issue, so refusing funds because it's a medical mainstream support. But the mainstream support pushing back saying it's a disability support, leaving participants without support and having to pay out of pocket.”

“Doesn't recognise the potential long-term MH impacts for autistic kids if done poorly - just kicking the cost of support down the road.”

2.2.5 Lack of Confidence due to negative language and framing

- **80%** described the Government’s language surrounding the Thriving Kids program as disrespectful, divisive, and gaslighting. Many warned that the Thriving Kids program was based upon an uninformed understanding of the Autism Spectrum. e.g.. “mild/moderate” terminology demonstrates a fundamental lack of clinical and lived experience of the diagnosis and of 0–8-year-old NDIS participants. This has created a lack of trust in the program and all that is associated with the proposed “NDIS reform”.

“If framed in the way Minister Butler has so far, it is reductive… Autism isn’t a temporary disability, and it isn’t overdiagnosed. We simply have generations before us who have gone undiagnosed!”

“While the announcement of changes to the NDIS was unexpected, it was not surprising. Reform is needed—but this is not the way to go about it. > > Neurodiverse people and families are being asked to trust a government body that continues to address us with language implying we are a burden. We are being asked to trust that you will do right by our community, while being excluded from the planning and development of a program that directly affects our lives. > > Those in charge have openly acknowledged their lack of lived experience and unfamiliarity with appropriate language. This is not a minor oversight—it is a fundamental flaw in the foundation of any program claiming to support neurodivergent children. > > Autism Spectrum Disorder and Developmental Delay are not mild or moderate mental health disorders. They are lifelong neurodevelopmental disabilities that impact the wiring of an individual's nervous system.”

"The language used is inappropriate and not neurodiversity affirming. If they don't understand this - how do they understand the perimeters of the program they are creating?"

“……Currently the language used is ignorant, outdated and offensive. Separating Autism as its own category exposes it to more criticism, scrutiny and misunderstanding…..”

80% of those responding to the Alliance’s survey demanded no rollout until meaningful co-design is achieved.

“This is not best practice, far less evidence-based.”

“The announcement alone has had a negative impact on the autistic community. … the lack of consultation with autistic people… has all been extremely stressful.”

2.2.6 Loss and Gaps in Trusted, Skilled and Resourced Specialists

- **73%** stress that trusted, skilled and resourced specialist providers are critical to hope and chances for a successful progression through childhood and beyond. Many are concerned that there would be a disruption of established rapport and trust with children leading to setbacks. Others fear that the program would rely on unqualified/ under-resourced providers, resulting in a decline in quality of care.

> *"I don't trust it at all. I think it will cause more harm than good. I really hope it's not mandatory. Our kids need to be comfortable with the therapists they work with for the therapy to be effective. Our children don't suffer fools telling them what they should be doing. I think it will destroy the self-esteem and identities of entire generation of Autistic children."*

> *"…….We need more information on what services woukd still be available to our kids. Mainstream schools are struggling as it is. They do not have the funding or resources to have adequate support……."*

2.2.7 Overreliance on the parents – financial, specialised supports and navigating new system

- **71%** say the program will increase financial and specialised support burdens upon parents. Many are currently without sufficient resourcing for early intervention and support, while others fear trauma and lifelong impacts on their Autistic children and other family members.

> *"Displacing and alienating autistic people and their families from supports resulting in devastating mental health effects."*

> *"Extremely traumatic and significant harm."*

> *"Lower socio-economic families will be most impacted as they will be unable to afford the specialist support needs of their children that will vary over time depending on events in their lives etc"*

"

2.2.8 Power imbalance created without choice and control

- **67%** stress the power imbalance created with a loss of choice and control of families due to centralised services and reliance on government providers, undermining local, community-based supports.

> *"…….Block-funded, one-size-fits-all services – Generic programs risk stripping away individualisation and choice, leaving children without the specific supports they actually need to thrive……."*

> *"what about protecting kids socially if they are perceived different in the public school structure because they are being pulled out of class missing education and being "othered".*

2.2.9 Lifelong Consequences due to Disruption of Supports at a Child's Critical Development Years

- **64%** stress about the uncertainty due to the potential loss of support at a child's critical time. Fears include disruption to early years access which is vital for long-term positive outcomes in education, social skills, and overall development, lack of clarity regarding alternative programs, those with fluctuating needs will fall through the cracks, absence of clear transition plans and lack of assurance of continued support after children age out of the program.

> *"Just know that so many parents are angry and fed up. I'm one of many. I just want my son to have his voice back… we've been promised the world too many times, hope is only a flicker we reserve for our children. Not for grand schemes and pipe dreams like his."*

2.2.10 Competition created for limited supports with non-NDIS children

- **62%** Concern that children will compete for already limited supports with other children not in NDIS.

2.2.11 Equity Gaps – Geographic, Intersectional, Two-Tiered System and Exclusion of Certain Groups

- **23%** Rural families and **12%** intersectional families fear further exclusion from access to supports available to others.

> *"Burnt out with two children on NDIS, yet other parents get support workers driving them around or access to Uber Eats and I'm left crying and unsupported from local MP following review meeting."*

> *"Young girls, gender diverse and people of colour are disproportionately affected by not being diagnosed or being diagnosed at lower levels because of the fact that they tend to be able to mask better and have higher social and emotional skills, they already are slipping through the cracks and going without diagnosis and if you are trying to syphon off the "milder" cases then it will be these demographics even though that's not fair."*

> *"Waitlists for Thriving Kids will potentially be long due to limited resources. Families in rural and remote areas are likely to be disadvantaged unless fly-in/fly-out services are also funded. There is likely to be inequity depending on family's geographical location, even in large cities, unless provider travel is fully funded. Will service eligibility drop out once a child turns 10?".*

> *"…….They are taking away individualised choice so creating a 2 tiered system of the people who can afford to still get their child all the supports and the ones that have to rely on the government system……".*

> *"It's creating fear. It's creating community divisions. It will create a tiered approach to care."*

2.3 KEY SUPPORT ABOUT THE THRIVING KIDS PROGRAM

Of the **9% mostly in favour** of the program almost all who saw potential in the program concept emphasised that positive outcomes would depend on successful program design and implementation, adequate funding and genuine co-design in partnership with individuals and families with lived experience of autism. While the **9% mostly in favour did** not achieve statistical significance in this survey we have included a reflection in the interests of delivering a balanced narrative to the Thriving Kids Parliamentary Inquiry. It also demonstrates what it is that people are aspiring to, and opportunities to build on to improve outcomes for our precious 0-8 year olds.

2.3.1 Increased Access and Reduced Financial Burden

- Some respondents pointed to the opportunity for the Thriving Kids program to extend supports to children previously excluded from the NDIS, or to those who struggle with out-of-pocket service costs.
- There were those who agreed that the potential for *"no Medicare gap payments"* or more equitable, local access to supports and therapies was appealing, especially if it means that *"children who don't qualify for the NDIS would have clearer pathways to support".*

"Providing more support through Medicare and in mainstream settings would be valuable especially for children who may have delays in one or two areas and are not diagnosed with global developmental delay…".

2.3.2 Simpler and More Integrated Systems

- Supporters stated that a well-integrated model, delivered through schools and local services, could reduce bureaucracy and be easier for families to navigate.
- There were those who agreed that Thriving Kids' vision of bringing *"health, education, and community supports into one system"* could streamline access and help make the NDIS sustainable for those with highest needs.

"If done well, it will be a fully integrated system that will provide great benefits for every Autistic child."

"I like the idea of my child receiving support in the school day which will make our lives less complex."

2.3.3 Early Intervention and Prevention Opportunities

- Some participants recognised the value in earlier developmental screening, coordinated support, and a mainstream system less rigidly tied to diagnosis.

"Faster diagnosis, earlier access to early intervention services—NDIS is a very long process, meaning you miss half of the early intervention window before gaining access."

"If the kids don't need a diagnosis but are identified as having needs…"

2.3.4 Long-term Inclusion and Thriving for All

- A number of respondents hoped, if robust and authentically co-designed, that Thriving Kids could help advance broader community understanding of neurodivergence, reduce stigma, and build inclusion.

"Potential to improve understanding of neurodiversity within schools, reducing pressure on children to comply with expectations that are not neurodevelopmentally appropriate…"

"Parents need better education."

"Hopefully Thriving Kids supports children to understand how they learn best, how to work with their strengths to be their best selves! I'm hoping there is suitable education on common ASD struggles such as anxiety and social skills."

2.3.5 Cautious Optimism and Calls for Proper Implementation

- Almost all (the significant minority) who saw potential in the program concept emphasised that positive outcomes would depend on successful program design and implementation:

"… if they truly happen, then it will be good. But I don't have faith that they will."

"If the new system can do some of these things I would be in favour but we don't know yet if it can…"

"There is possible positives such as no gap, services for kids that don't qualify for NDIS and increased access to diagnosis and assessment. Those things could be very good. They should be established first before removing children off the NDIS…"

"There are so many children currently without access to supports because of various issues including long public wait lists and parents being unable to afford private assessments and therapies."

Appendix 3: Fifteen Clear Government Steps to help build trust and move towards a constructive partnership in the timeframe

Below are clear steps to help turn fear into trust and move towards a constructive partnership with the Autistic and autism community. These steps are prudent for good governance, are based on our expertise and experience, directly address the top fears and responses to the question in our survey “What additional information would help you form your opinion about Thriving Kids?". These steps are in no particular order. Refer to 3.2 Project Timeline where we have attempted to apply these to the Government’s provided timeline, noting we have identified that there should be a pause of the Thriving Kids program until the Parliamentary Inquiry recommendations have been heard and there has been meaningful coproduction.

This is a once-in-a-generation chance where we can move from fear to hope together - and ALL children can thrive.

3.1 FIFTEEN CLEAR GOVERNMENT STEPS

1. **Reframe the Narrative via Public acknowledgement**
   The government should publicly acknowledge community concerns including the language used in the Thriving Kids announcement (lifelong, mild/ moderate etc), and reframe the narrative, adopting strengths-based, neuro-affirming communication aligned with the National Autism Strategy that respects Autistic individuals and their families. The government should also challenge discriminatory narratives to ensure Autistic individuals are treated with dignity and respect.

2. **Balance Representation**
   Balance the Thriving Kids Advisory group, ensuring that one-third of the representatives are individuals/ families, so “evidence-based” is followed with three equal pillars (research, evidence in practice and individuals/ parents). Also, Thriving Kids targets Autistic children, ensuring there is appropriate representation and subcommittees.

3. **Pause for Genuine Co-Design and Pilots**
   Pause any Thriving Kids Program rollout until:
   a) Parliamentary Inquiry recommendations are provided and integrated.
   b) Meaningful Co-Design is complete using universal design -that is, funding and launching towards meaningful and respectful co-production (design, delivery and evaluation) of practical supports with Autistic people, families, representative organisations and the rest of the community (with them and not to them).
   c) There is commitment and planning as a Priority to Equity and Accessibility (refer to Section ToR 3.
   d) Evidence-based piloting occurs and independently evaluated (refer to Item 5 in this section). This can be in stages so that evidenced based effective programs that exist can be piloted and scaled in short timeframes.

4. **Provide immediate commitment to no-gap protections and pause any NDIS reassessments for affected children until validated alternatives exists**
Refer Section ToR 6 for a safe transition and explicitly add guardrails – including **no-gap protections**, so that no child loses existing supports before new, safe, validated suitable, affordable and accessible support alternatives are in place and proven to work and gaps in underserved areas are addressed.

5. **Develop and Publish a Transparent Roadmap with Clear Readiness-Based Rollout Plan** (refer Section 3.2)

This includes providing clear communication about:

a) program scope, structure, goals, eligibility criteria, delivery mechanisms, implementation, funding levels, and out-of-pocket costs, including how it aligns with tiered foundational supports as recommended in the NDIS Review, how services would be tailored to individual needs and accessibility for families in rural and remote areas.
b) theory of change concept, outcomes framework, and evidence-based design (to ensure the program's effectiveness and safety).
c) funding, including state/territory commitments
d) participant cohorts (NDIS and Non-NDIS participants),
e) independent evaluation and delivery of rapid pilots (diverse sites), with timelines, research, independent evaluation using national guidelines (e.g Autism CRC guidelines), and real-time feedback mechanisms involving published pilot criteria and metrics in advance.
f) a first-year action plan including:
    - the establishment of a baseline of how many children are targeted to go into the Thriving Kids program (to avoid the lessons learnt from the NDIS that these are not the numbers we expected)
    - to identify and evaluate the effectiveness and gaps of supports and services that exist (similar to National Autism Strategy, noting this should leverage off of some of those commitments and strategies)
    - to assess and learn from funding models in other sectors, including alliance-based risk/ reward, open book cost plus, and performance-based contracting and capacity building grants. This also includes methods to fund small, high-impact community enterprises with sustainable commercial terms.

Make this plain language and translated.

6. **Build Accountable, Integrated Governance with a Safe Vertically and Horizontal Transition Plan building first on what exists**

Involving Federal/ State and Territories, Local Government and community as outlined in Section ToR 6 and Appendix 4).

This includes:
a) Government providing oversight of the entire program, having joint horizontal and vertical cross-government outcomes and accountability so there is integration with existing systems (education settings, healthcare and community supports)
b) Use of government levers (ToR 6) to strengthen existing systems and deliver targeted and accountable action in government systems such as education, employment, and health outcomes, with enforceable human-rights obligations so this investment can be realised. Make providers be subject to qualification, rules, and ongoing auditing.
c) Build on what exists, that is validated as effective. If not proven undertake pilots and wait for verified results before national rollouts
d) Systems for monitoring providers, safeguarding policies, and clear pathways for reporting concerns are necessary to ensure quality and prevent exploitation.

7. **Transparency through a Communication Plan and Public Reporting of Data**
Build trust through regular, transparent, and accessible grass roots-facing communication as soon as various elements are known, with evidence that before scaling a national support pathway material used are co-designed and have been successfully piloted.

This includes public dashboards on access times, service mix, workforce distribution, outcomes, and equity (rural/remote, First Nations, low-SES), with independent evaluation against national guidelines (e.g., Autism CRC) and opportunities for feedback.

8. **Align with National Strategies and fully fund implementation** including the National Autism Strategy (and accelerate First Action Plan), the National Roadmap to Improve Health & Mental Health of Autistic People (2025–2035) and **Disability Royal Commission recommendations –** including those agreed in principle. The program needs to align with the National Autism Strategy to improve outcomes for Autistic individuals and to improve community awareness and challenge bias and stigma.

9. **Commit to a focus on Long-Term Support and Continuity of Care**
Start the preliminary planning to build a longer-term focus on support, including what's next when children turn 9 to ensure continuity of care and avoid leaving children without support as they age out of Thriving Kids. This supports the call to recognise autism as a lifelong condition and ensure supports extend beyond early childhood to address fluctuating needs over time.

10. **Establish Independent Oversight**
Assurance of safeguards by including an independent evaluator reporting to Parliament and an Independent Audit to explore complaints and report.

11. **Guarantee Early Identification and Referral**
Refer ToR 1 and Appendix 6

Guarantee national access to validated screening and mandate training for GPs, maternal health nurses, and educators on developmental surveillance and autism-affirming practice.

12. Prioritise Parent and Families Empowerment

Refer ToR 1, ToR 6 and Appendix 6

a) Fund autism-specific first steps programs that work alongside parents from the beginning
b) Fund parent-mediated interventions that focus on communication, sensory regulation, and play.
c) Reinstate and fund fully early pathway supports such as autism advisors, information helplines, and early-day workshops (refer ToR 2 response).
d) Ensure family supports by investing in navigators, peer supports & mentoring, independent advocacy and respite. This includes prior to diagnosis and for Thriving Kids program transition so families do not carry the transition burden.
e) Invest in supports for siblings.

13. Create a National Workforce Strategy with Tiered National Competency Framework

There is a need to build a competent, diverse neuro-affirming, skilled workforce informed by evidence and autistic lived experience so that provider quality and therapy consistency are central to well-being within the current and future autism community. This includes accredited training, training subsidies, rural incentives, specialist recognition, supervision. This provides assurances about provider qualifications, training, scopes of practice clarity and monitoring to ensure high-quality care.

14. Mandate Neurodiversity-affirming Standards and Guiding principles for Thriving Kids Program

A mandate of neuro-affirming standards and guiding principles provides safeguards to cut across practices and programs to require commitment and alignment built in, respect for Autistic identities and prevent harmful practices, conflict of interest and ensure providers deliver evidence-based, respectful, and appropriate individualised supports. As part of ensuring the commitment, there should be well-being measures that follow the child and the parent over time.

15. Economic Sustainability Test: Invest to Avoid Lost Potential

Build the model and/ or undertake a parliamentary inquiry that recognises the costs of lost potential and the gains of participation and prioritise investments that show long-term social and economic returns (education completion, employment, carer workforce participation etc) and the associated accountability safeguards that are required.

3.2 READINESS DEPENDENT ROLLOUT

It has been reported by the Government that the Thriving Kids program will begin rolling out services on July 1, 2026, with the first services available from this date. The rollout is expected to take 12 months, aiming for full national services to be in place by mid-2027, in time for broader changes to NDIS access arrangements. Timelines given are:

- **2025:** Program design will be finalised through a collaboration with State and Territory governments.
- **July 1, 2026:** The first services for the Thriving Kids program are expected to become available.
- **July 1, 2026 - June 30, 2027:**
  A 12-month period of phased rollout will occur to ramp up services across the country.
- **Mid-2027:**
  Broader changes to NDIS access arrangements are anticipated to take effect, with the program fully transitioned by this time.

Any timeline should be considered in the context of the 11 Essential Principles as preconditions and evaluation criteria for the Thriving Kids rollout (identified in Appendix 4).

The most critical is Principle 11. “No Go if Not Ready” – which is having the courage to:

1. Pause and get the planning right as in the end this will save significant dollars in the long run. This will also allow time to identify the 20% of activities that will provide the 80% of sustainable impact
2. No Go if the Whole of Reform Ecosystem is Not ready
3. No Go at an individual level for those elements that have not been validated to avoid disrupting a child’s or children’s critical developmental pathway.

Timelines must be readiness-based, not date-based. A phased rollout from 2025–2028 with staged pilots, workforce accreditation, and independent evaluation will ensure safety, trust, and sustainability.

Appendix 4: Our 11 Essential Principles for Reform

4.1 Principles as Preconditions and Evaluation Criteria

To get this right, we call for government to adopt 11 essential principles as preconditions and evaluation criteria for Thriving Kids rollout.

1. **Co-produced from the Start**
   Every stage (design, pilot, implementation, evaluation) is co-produced (using universal design) by Autistic people, families and representative organisations that must be funded, accessible, and remunerated.

2. **No-gap protections guarantee**
   Pause NDIS removals and eligibility reassessments until validated alternatives exist and are proven fit-for-person. No child loses funded supports until a safety net is independently confirmed.

3. **Pilot, evaluate, scale — in that order.**
   Staged pilots (including rural/remote and priority cohorts), independent ethics review, and public reporting before any national roll-out. Pilots must include diverse personas (complex communication needs, high-masking, intersectional identities).

4. **Human-Rights Anchored, Neuro-Affirming Standards**

   a. **Neuro-affirming: Strength-based, flexible, trauma-informed and culturally safe practice** banning use of compliance/ normalisation-focused interventions where harm is shown.
   b. **Three-pillar evidence-based standards -** are adopted in testing and practice – grounded equally in research, evidence in practice, and individual /family preference and values (choice and control). Use of Autism CRC and PRECI/ECI guidance as minimum standards for testing, selection and delivery of supports.
   c. **Human Rights at the centre -** with alignment to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) to create a positive duty of care and achieve equity and intersectional confidence.

5. **Fit-for-Person Life-Span Approach in a universal system.**

   Build a generalised, accessible ecosystem in mainstream settings (health, education, childcare) with clear, low-friction on-ramps to funded, individualised supports when needed — flexible, short-term, intensity-matched. This provides for the principles of:
   a. **A life-cycle systems approach** – supports available at the right time, right place, right level.

  b. **Fit-for-person supports** – individualised (not cookie cutter), trauma-informed, culturally safe, neuro-diversity affirming supports providing for choice and control in an individual's environmental context (holistic approach).

6. **Competent Autism Specialists in a Mainstream Environment**

   Trained, recognised autism specialists, not generalists alone, within a funded competency framework and national workforce strategy (accredited training, supervision, rural incentives. protecting autism specialist disciplines and scopes of practice while expanding community-based roles.

7. **Transparency and Accountability**

   Provision of transparency and accountability through independent oversight, public dashboards and real-time evaluation to support access, equity, outcomes, safeguards and removal of harm.

8. **Long-Term Outcome Evaluation**

   Measure investment based on long-term gains to the individual, family, society and Australian economy and not short-term returns. This includes recognising the costs of lost potential and the gains of participation. This longitudinal evaluation and cost–benefit modelling is to show Return on Investment and secure bilateral and societal support.

9. **Cross-government Shared Accountability (Federated Governance)**

   Government is responsible and accountable for cross-government outcomes, including addressing gaps that are respectful to individuals rather than the individual/ parent/family responsible for navigating the gaps.
   (Refer Appendix 5 for Accountable Integrated Governance with A Safe Vertically and Horizontal Transition Plan)

10. **Build on What Exists** rather than creating government driven labour forces.

11. **No Go if Not Ready**

    The courage needs to exist for a no-go decision so as to delay or modify any element of the Thriving Kids program not validated by evidence.
    A 'No-Go if Not Ready' safeguard is not resistance — it is responsible governance. Proceeding prematurely risks irreparable harm to children's developmental trajectories and public confidence. The government must have the courage to pause or stage implementation where readiness, evidence, or safety are not yet proven. This principle ensures that reform is enduring, ethical, and economically sound.

Appendix 5: Accountable Integrated Governance with A Safe Vertically and Horizontal Transition Plan

This Appendix sets out a proposed Accountable Integrated Governance Framework supported by a Safe Vertical and Horizontal Transition Plan, as recommended in our response to ToR 6.

The purpose of this framework is to ensure that any transition from NDIS-funded supports to the proposed *Thriving Kids* model is safe, measurable, accountable, and non-regressive, and that no child loses support in practice or effect during or after transition.

The Transition Plan must commence while children remain in the NDIS, not after supports are withdrawn, and must clearly demonstrate how each currently NDIS-funded support will be matched or bettered under the Thriving Kids model, with measurable KPIs, timelines, safeguards, and accountability mechanisms.

5.1 The Vertical and Horizontal Integration Model

The proposed model integrates responsibility, funding, accountability and outcomes **vertically** (across levels of government) and **horizontally** (across systems such as disability, education, health and community services). It operates across three interdependent levels.

5.1.1 Federal Cross-Sectional Level

At the federal level, government must establish the **legislative, funding and accountability architecture** that guarantees safe transition and prevents loss of supports.

Core requirements

1. **Individual Transition Plans**
    - Require government to provide a **Transition Plan for every child**, showing how each current NDIS-funded support will be **matched or bettered on an outcomes basis** under Thriving Kids.
    - Each plan must include:
        - Clear outcome equivalence or improvement
        - Measurable KPIs
        - Defined timelines
        - Named responsible systems and services

2. **Concrete Transition Guarantees**
   Government must legislate or formally guarantee:
    - No child is off-ramped from NDIS until a **verified alternative is operational**
    - Statutory entitlements to **continuity of care**
    - Formal dispute-resolution and appeal pathways
    - Funding continuity during transition periods so families are not left in limbo

3. **No-Gap Protections**
    - Enshrine **non-regression and no-gap protections** in legislation or binding rules.

    - Existing supports must remain in place until validated alternatives are proven to be:
        - Available
        - Accessible
        - Appropriate
        - Capable of delivering equivalent or better outcomes

4. **Monitoring and Oversight**
    - Require monitoring of every child's supports on an outcomes basis.
    - Establish independent oversight and reporting against national KPIs.

5.1.2 State-Based / Territory / Local Level

States, territories and local systems are responsible for **standing up and sustaining mainstream capability**, particularly in education and community settings.

Mandated co-design and standards

- Require co-design of Thriving Kids implementation with:
    - State and territory education systems
    - Representative disability organisations
    - Parents and carers
- Co-design must address:
    - Common language and practice standards
    - Referral pathways
    - Teacher and school resources
    - Transition timeframes

Why this matters

- Prevents duplication, mismatch and fragmentation between NDIS-funded interventions and school practice.
- Aligns with calls for extended transition timeframes and genuine system readiness.

Levers

- Condition Commonwealth funding on:
    - Co-design milestones
    - Public release of jurisdictional transition plans
    - Evidence of workforce readiness and uptake
- Require access to:
    - Communities of practice
    - Supervision and mentoring during transition and post-transition periods

5.1.3 Individual Level (Participant / Student with Teacher)

At the individual level, the model centres on the **child, family and frontline educators**, ensuring transitions are safe, person-centred and supported by the system.

Key features

- Transition objectives are embedded **with informed consent** and do not disrupt existing NDIS goals.

- The burden of knowledge transfer is **shifted away from families** and onto funded systems.

Each child's plan must include:
- Child-focused functional outcomes
- Teacher/school capacity outcomes
- A clear transition pathway with timelines and named mainstream services
- Safety mechanisms to pause or reverse transition if outcomes are not met

5.2 The Transition Points and Levers

This section identifies **when** transition actions must occur and **which levers** governments, NDIA, providers and schools must use to ensure accountability and safety.

5.2.1 Federal Cross-Sectional Level: Transition Points and Levers

Data, outcomes and shared KPIs
- Establish privacy-compliant data-sharing protocols between NDIA, Thriving Kids and state education systems.
- Implement shared outcome measures across systems.

System levers
- Pooled funding arrangements
- Conditional Commonwealth–state agreements
- Shared KPIs
- Independent oversight and public reporting

Transition safeguards (No Gap, No Loss)

The Committee should require government to guarantee:
1. A Transition Plan for each child with KPIs and timelines
2. No withdrawal of NDIS supports until alternatives are proven operational
3. Statutory continuity of care
4. Formal dispute-resolution and appeal mechanisms
5. Funding continuity throughout transition

5.2.2 State-Based / Territory / Local Level: Transition Points and Levers

Workforce uplift and system readiness
- Pool a portion of Thriving Kids funding to support:
    - Workforce training and professional development
    - In-mainstream coaching and co-delivery
    - Staff relief time and resources

Knowledge products and communities of practice
- Require deliverables from funded capacity-building, such as:
    - Teacher manuals
    - Video micro-lessons
    - Fidelity checklists
    - Classroom prompts
- Store these in a national repository to create sustained institutional memory.

Levers

- Contractual requirements for demonstrated school capacity transfer
- Conditional funding tied to school uptake and implementation
- Provider contracts requiring co-delivery and teacher training
- Recognition of nationally consistent micro-credentials as formal professional development
- Payment-by-results or milestone-based payments linked to verified school capability outcomes

5.2.3 Individual Level: Transition Points and Levers

Transition process

a) **Embed transition to mainstream objectives in the year of transition** to the relevant mainstream setting by creating an S10 In list transitional guidance and support category. For instance, in a school environment, this would include:
  - explicit co-goals: (a) child functional outcomes, (b) teacher/school capacity outcomes, (c) an exit/transition plan with timeline and named mainstream service(s).
  - have capacity-building funding line items *dual-purpose* — not only child-facing therapy but sessions with teachers/school staff (co-planning, modelling, written resources). This will ensure capacity-building so the *school* can continue the relevant intervention related to an education setting.
  - NDIA guidance/planner templates; make teacher-capacity activities an allowable cost under capacity-building items in S10.
  - co-delivery and co-training: fund co-delivered sessions where the therapist and teacher learn together. This might be a proportion of therapy hours to be delivered as in-school co-teaching/coaching with the classroom teacher present, plus follow-up written plans for the teacher.

b) **Create Government levers with accountability.** This would include:
  - Demonstration of school capacity transfer by educators. A practical example could be that NDIA require evidence (teacher sign-offs, in-class observations, school action plans) as part of plan outcomes.
  - Plans must contain measurable teacher-capacity indicators and school-level implementation KPIs (e.g. percentage of target strategies implemented by teacher independently at 3 months).
  - Use the NDIA evaluation mechanisms for S10 changes to include these KPIs.

This will avoid the “participant/parent transferring the knowledge to the “teacher” and shift the implementation burden to the system by funding teacher upskilling as a funded activity and making the education setting responsible.

Funding

For avoidance of doubt, this is additional funding for schools and therapists to achieve the transitional goals by transferring knowledge and capacity building.

If the government does not have an effective mechanism for this funding per child, then the NDIS could make a “teacher-capacity” activity as an allowable cost under Capacity-Building items in

S10 while the child remains in the Scheme. This could occur under the S10 transitional guidance and replacement support processes.

Making knowledge transfer measurable

- Mandate:
    - Co-delivered therapy and in-class coaching
    - Written plans and resources for teachers
    - Evidence of implementation (teacher sign-offs, observations, school action plans)
- Include measurable teacher-capacity indicators and school-level KPIs (e.g. percentage of strategies independently implemented at 3 months).

Safeguards and verification

- Require verified evidence that mainstream supports are available and capable **before** withdrawing NDIS funding.
- Mandate staged withdrawal with guaranteed overlap (e.g. 6–12 months).
- Ensure continuity across life stages, including entry to school, grade transitions and post-school pathways, supported by profile passports so families do not have to “start over”.

Conclusion

This **Accountable Integrated Governance with a Safe Vertical and Horizontal Transition Plan** ensures that responsibility, capability and accountability sit with the systems that control outcomes, not with children and families. By combining legislative safeguards, conditional funding, measurable KPIs and co-designed implementation, it delivers a transition framework that is **safe, rights-based, non-regressive and genuinely fit for purpose**.

Appendix 6: Early Diagnosis and Access Pathway – Neurodevelopmental Superhighway

6.1 Overview

A best-practice early diagnosis and access pathway must be **universal, family-centred, evidence-based, and neurodiversity-affirming**. It should ensure that children and families can move seamlessly from *concern to understanding to support* — regardless of geography or income.

Four success factors are:

1. **Early, accessible developmental surveillance and diagnosis** (with reduced wait times and no-cost access).
2. **Parent empowerment and co-learning** from the start.
3. **Continuity between early intervention, education, community systems**, **and NDIS** rather than fragmented handovers.

   That is, it is not an either /or system but more a "right door" system where each of these systems works together to "open" the right door to access appropriate services and supports. As there is available at each door the right skills, at the right time, based on individual needs/ values/preferences, it is unlikely there will be exploitation of "too" much therapy or "ineffective therapy". At the same time, we won't have children falling through the gaps. Children can have "access" to a NDIS plan all the time but at any given time there may be a $0 allocated as the "other systems" are meeting the needs.

   This model would be consistent with the NDIS Review tiered model imagined with:

   1. Generalised supports through community and mainstream systems
   2. Targeted supports such as Thriving Kids
   3. Specialised supports

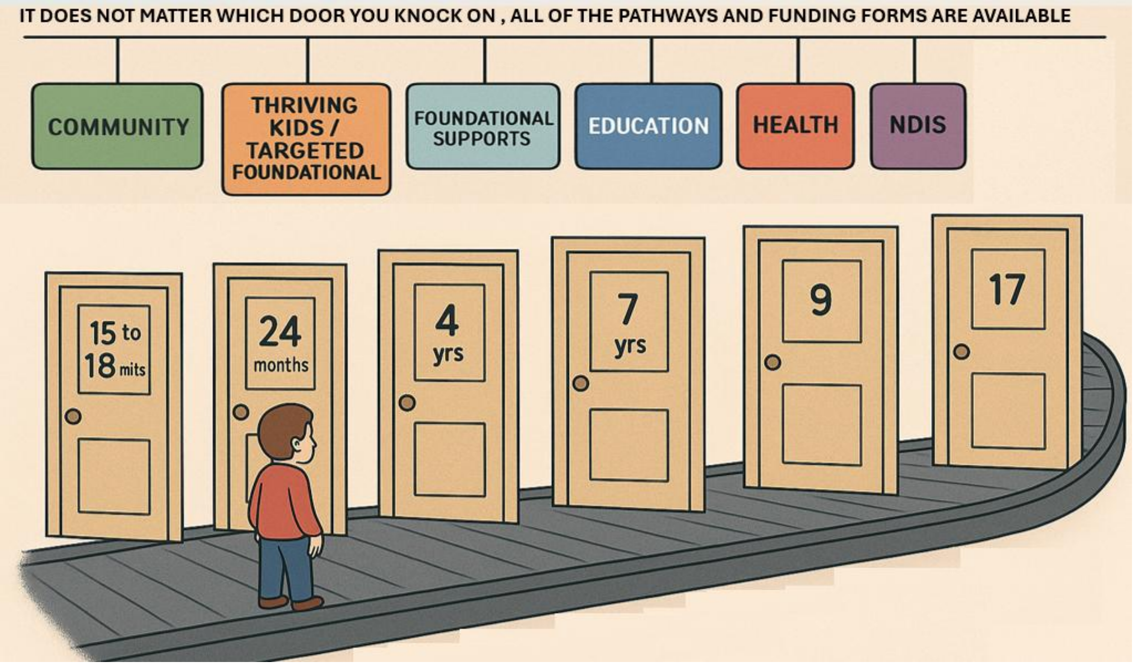
4. **Safe pair of independent early-year childhood expert hands to navigate throughout the entire period for consistency and to also "check in" at key points to ensure the child and families are staying on path.**

   This is rather than relying on generalists to make critical decisions and provide guidance using standardised tools at government decision gates at a child's critical developmental stages, who rely on various assessment tools at government decision gates.

IMAGINE:

An Early Diagnosis and Access Pathway – A National Neurodevelopmental Superhighway, where the Early Diagnosis and Access Pathway establishes a nationally consistent, neurodiversity-affirming framework ensuring that every child or young person can be identified early, assessed promptly, and supported continuously, without financial or systemic barriers.

The pathway operates as a "neurodevelopmental superhighway" with multiple entry and exit ramps and clearly sign-posted doors to the right level of support.



It integrates universal, targeted, and specialised services across health, education, and social sectors, ensuring that no individual is left without a defined route to assessment and support.

To visualise the **Neurodevelopmental Superhighway elements** the following description is provided:

- **Main Superhighway:** Represents the universal developmental pathway all children travel along (mainstream and community supports).
- **Entry Ramps:** Points of first concern — parent observations, GP visits, early education reports.
- **Exit Ramps:** Lead to the "Right Door by age and transition point but each door considers the three tiered system so that it is an integrated hub and there are not accountability gaps where its decided what extent you need Path 1: Community / Foundational Supports, what extent you need Path 2: Targeted (Thriving Kids) Supports and what extent do you need Path 3: Specialised (NDIS) Supports.
- **Navigators:** Represented as signposts or guides stationed along the superhighway in each local area, ensuring each child and family takes the correct ramp and can re-enter seamlessly as needs change.

- **Re-entry Points:** Allow people diagnosed later in life to join the highway at any stage — adolescence, adulthood, or older age — with access to assessment, education, and supports.
- **Quality Gates:** Symbolise trained professionals, standardised tools, and cross-system collaboration at each major transition.

While this pathway is anchored in the early years, it is also designed to be lifespan-inclusive. Many Autistic people receive a diagnosis later in life — in adolescence or adulthood — often after years of unmet needs. The same "superhighway" principles apply: clear entry points, independent navigation, no-cost assessments, and neurodiversity-affirming supports that can activate at any age or developmental stage. This ensures the system remains responsive across the lifespan, not only the early childhood window.

WHY THIS WILL WORK FOR ALL STAKEHOLDERS:

a) As this will have **supports ebb and flow as needed** in the right amounts to address the government's **concerns of overservicing** and also **reduce the scarcity model for individuals and parents**. That is, the fear that their child's needs will be capped, that the right door will not be there at the right time, that behind the door is not a safe pair of informed, knowledgeable and consistent hands and that they will once again fall through gaps between systems. The key issue is that systems are not yet equipped as outlined in this document.

   When families **know there is a reliable, safe, individualised pathway** – a system that is both generalised and inclusive but can switch on fit-for-person specialised support at the right time, for the right amount, by the right expertise, in the right environment – they do not cling to scarcity. Instead, they can participate, contribute, and thrive alongside the rest of the community knowing safeguards exist.

b) **Is easily scaleable to regional/remote and extendable to subsequent developmental years – 9 years onwards**

c) **Makes the appropriate government system accountable at the right time** rather than handballing children/ people between systems.

OTHER BENEFITS:

Alignment with other National Instruments

This model aligns with the *National Autism Strategy* (Commitments 11–15), the *National Roadmap for the Health and Mental Health of Autistic People*, and the recommendations of the *NDIS Review*.

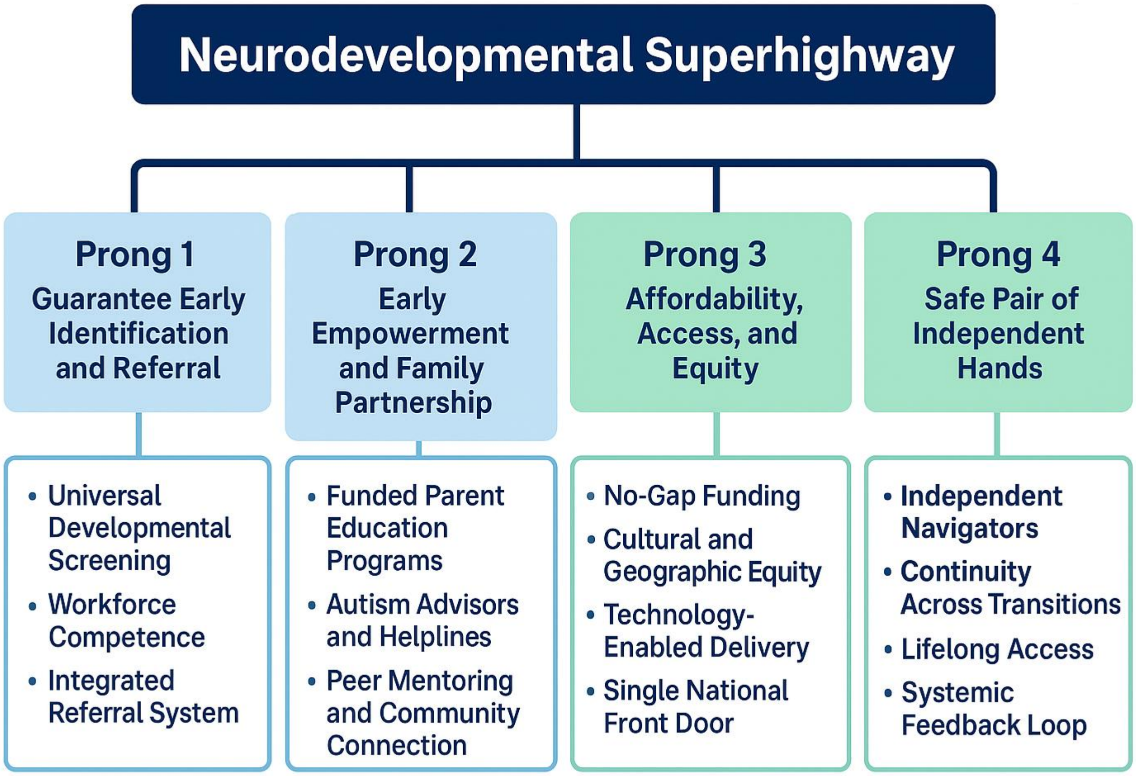
This is also consistent with Step 11 and 12 in **Appendix 5: 15 Government Steps to Build Trust.** That is:

1. **Guarantee Early Identification** — National validated screening access and mandatory autism-affirming professional training (for GPs, maternal health nurses, and educators on developmental surveillance and autism-affirming practice).

2. **Prioritise Parents and Families Empowerment—** Fund autism-specific first steps programs that work alongside parents from the beginning
    a. Fund parent-mediated interventions that focus on communication, sensory regulation, and play.
    b. Reinstate and fund fully early pathway supports such as autism advisors, information helplines, and early-day workshops (refer ToR 2 response).
    c. Ensure family supports by investing in navigators, peer supports & mentoring, independent advocacy and respite. This includes prior to diagnosis and for Thriving Kids program transition so families do not carry the transition burden.

6.2 The Four-Prong Model

The success of this would be on the following four prongs as outlined I the table below and then described in more detail.



- **Regional Equity:** Embed tele-assessment capacity and mobile outreach teams to ensure equitable access for rural, remote, and CALD communities (NAS Commitment 15).
- **Accountability Metrics:** Publish annual national data on screening participation, diagnostic wait times, and equity outcomes.

6.2.1 Prong 1 — Guarantee Early Identification and Referral

Objective: Every child has access to universal, validated, neuro-affirming developmental surveillance, screening and diagnostic assessment and seamless referral pathways (without delay or cost).

Key Mechanisms

- **Mandate Universal National Developmental Surveillance**
  Integrate autism-specific and developmental screening into standard child health checks (per NAS Commitment 14). Do this at key ages (15, 24, 36 months).
  Use validated tools such as **ASQ-3, PEDS, and M-CHAT-R/F**.**PEDS**, **ASQ-3**, supported by parent-led developmental tracking via the **Raising Children Network**.
  Borrowing from the **UK "Early Identification Pathway" Model** there is a **mandatory developmental surveillance by health visitors at 2 years.**
  2 years is not too young to be assessed. Other testing such as hearing can start as early as 16 months so that by the time a child is 2 years, they could be having an assessment undertaken.

- **Parent as First Responders**
  Empower parents as early identifiers through public education and free access to digital checklists and milestone trackers.
  Recognise parents as **co-assessors**, not passive informants, within diagnostic evaluations.

- **Create a Nationally Government Funded Integrated "Access Vouchers" Referral System**
  Create funded "Access Vouchers" guaranteeing *gap-free diagnostic assessment* redeemable through accredited public or registered private providers, with flexible options for underserved areas. Fully subsidised assessments reduce inequity and prevent "diagnostic lotteries. This should extend to early supports during key life transitions (early years, preschool, primary, secondary, and adulthood).

- **Fund Integrated Child Development Hubs**
  Have community outreach models that are multidisciplinary hubs co-locating paediatric, allied health, educator services and navigators, operating under shared care plans.

- **Collaborative planning** between health, education, and community services for smooth transition to preschool and school.

- **Embed trained navigators** in early childhood and health settings to to guide families from first concern through assessment and into appropriate supports, including ensuring every referral leads to timely assessment.

- **Workforce Competence**
  Establish **standardised national accredited training and periodic supervision** for all professionals in developmental surveillance, identification, and autism-affirming

assessment, ensuring cultural safety and gender bias mitigation, aligned with NAS Commitment 11.

- **Train all primary touchpoints** — GPs, child and family health nurses, early educators — in neurodiversity-affirming developmental observation.
- **Develop a Shared Digital "Child Development Passport"**
  Implement secure shared digital records to streamline information transfer through transitions, minimise repetition, and protect continuity across health, education, and social sectors. This should contain screening results and reports.
- **Monitor and publish outcomes including wait times and access data** to enforce accountability and continuous system review.

6.2.2 Prong 2 — Prioritise Early Empowerment and Family Partnership

Objective: Families are informed, capable, and supported from the moment of concern — not only post-diagnosis. This also prevents dealing with issues when in a crisis.

Key Mechanisms

- **Parent Learning and Coaching -** ***Parent-Mediated Interventions***
  Fund and expand early-year developmental and relationship evidence-based parent-mediated programs consistent with PRECI and Autism CRC guidelines, like Hanen "More Than Words", Early Years, to be available immediately upon referral or developmental concern.
- **Pre- and Post-Diagnosis Information Packages**
  (NAS Commitment 12) Develop accessible materials in multiple formats (plain English, Easy Read, video, and CALD translation) explaining the diagnostic journey, expectations, and available supports.
- **Family Navigation and Independent Advocacy Supports**
  Reinstate **autism advisors** and have funded **navigators** to assist families through systems and transitions (refer Prong 4). This should include funded check-ins.
- **Autism Helplines:** Also reinstate/ fully fund information help lines like Autism Connect.
- **Peer Led and Community Networks**
  Build family confidence and reduce isolation through **peer-led programs** (MyTime, PlayConnect+, Envisage).
- **Offer respite** from first concern through diagnosis and transition.
- **Data and Quality Accountability**
  Parents act as **partners in accountability** — tracking progress, providing feedback, and ensuring providers uphold neuro-affirming and evidence-based standards.

- **Peer Mentoring and Community Connection:** Support structured peer networks, respite, and advocacy from early stages through transition.
- **Navigator Continuity:** Ensure a single professional point of contact follows each family through diagnosis, school entry, adolescence, and, where relevant, transition to adulthood.
- **Parent Capacity Building:** Deliver practical learning on developmental milestones, service navigation, and advocacy, through blended online and in-person formats.

6.2.3 Prong 3 — Affordability, Access, and Equity

Objective: Guarantee equitable, affordable, and culturally safe access to developmental services.

Key Mechanisms:

- **No-Gap Funding:** Integrate Access Vouchers, Bulk Billing and dedicated Medicare items to eliminate out-of-pocket costs (NAS Commitment 13).
- **Equity-Based Funding (Cultural and Geographic)**: Allocate resources based on socioeconomic and geographic need (rural, remote, First Nations, CALD communities).
- **Certification Framework for Neurodiversity-Affirming Practice**: Implement an **accreditation “tick” model** allowing families to identify certified neuro-affirming providers.
- **Single National Front Door:** Establish a centralised digital referral and navigation platform mapping available services, eligibility, and funding.
- **Technology-Enabled Delivery:** Expand telehealth and digital monitoring platforms to reduce travel and wait-time barriers.
- **Service Streamlining:** Reduce administrative duplication by harmonising health, education, and social-care referral processes.

Voucher System to deal with the scarcity of resources

Given the scarcity of resources ideally there would be a voucher system where families could access supports from appropriate environments that already exist in the community. Examples may be:

1. early childhood specialists with a developmental educator background or other early childhood training
2. nurses who could undertake early childhood training

3. independent disability advocates who understand the local community and mainstream services and disability

All of these roles require or should require person-centred, trauma-informed and culturally aware competency.

The benefits are:

1. these skilled individuals could have their skills remain contemporary due to evidence in practice.
2. these roles already exist in the community, rather than creating an isolated pool of resources in NDIA, who are not independent and would either drain the existing ecosystem or take years to develop and retain the breadth and depth of skills required.

These roles could also be used to help build capacity by delivering training to both families and also train the trainer.

6.2.4 Prong 4 — Safe pair of independent early year childhood expert hands to navigate.

Objective: Provide consistent, impartial expertise guidance and coordination throughout the lifespan, rather than generalists relied on to apply various assessment tools at government decision gates

Key Mechanisms:

- At key touch points decisions as to which system a child should enter following the three-tiered system that the NDIS review referred to should be undertaken by an early year's expert given the diversity and complexity of disability:
    - Generalised Foundation Supports (Mainstream and Community)
    - Targeted Supports (Thriving Kids Program)
    - Specialised Supports (NDIS)
- The alternative is a risk that we should not be willing to take given how precious all children are. The necessity for children to get on the right developmental path with the right supports in place at the right time delivered in the right quantity and right quality. This is not a time for negotiation and discovery.
- To date suggestions that this could be generalists taught how to use various tools is not considered appropriate as this is not an administrative task. There is an art and science to this role that cannot be left to chance. It is essential that roles such as these have access to ongoing supervision and contemporary training accessible within a community of practice learning hub.
- This type of role would also be in a better position to develop community connection plans.

6.3 Domestic and International Reference Points that Support the 4-prong model

Domestic Experience

- **Early Childhood Specialists (Early Year Navigators)**

  Prior to the NDIS, there were early childhood specialists that existed within State and Territory peak bodies. This was block funded. These early childhood specialists would be a safe pair of hands that supported navigating families through:
  - community supports, mainstream systems and specialised supports;
  - key transition from childcare to preschool to primary; and
  - the parents' learning journey

  This would provide a safe pair of independent qualified hands that is guiding and making gateway assessments mitigating the risk that at a critical time in a child's development pathway the wrong decision is not made as to which door or doors should be accessible.

- **Child and Family Health checks (0–5 years)** – routine developmental surveillance using ASQ and PEDS in some states (NSW, VIC).

- **NSW "Brighter Beginnings" and SA "Early Childhood Development checks"** – the aim to identify issues early but coverage is inconsistent.

- **NDIS Early Childhood Approach (ECEI)** – previously funded early supports pre-diagnosis but now being restructured under "Foundational Supports."

- **Autism State/ Territory-Based Peak Bodies** – offered free early-day workshops, autism advisors, and helplines — this is a proven template.

- **Integrated Child Development Hubs**
  Pre-COVID organisations such as Autism SA operated specialised foundational supports centres in the same hub as childhood/ pre-school centres allowing children to build capacity as few days a week and apply those skills in mainstream for the remaining week. When challenges were experienced in mainstream, a member of the foundational support team would go and observe, support and transition knowledge to the mainstream educator.

  Early Year Childhood specialists that were block funded were also available to drop in and support educators in early year settings. When a child transitioned to primary school there were school inclusion consultants who would support that transition. If you were fortunate as in SA, the consultants were assigned to regions the same school inclusion consultant might be part of that student's life through all their education journey.

International Experience

- **UK "Early Identification Pathway" (NICE Autism Pathway)** – There are national diagnostic standards with mandatory local implementation and reporting. Every local authority has a clear autism assessment route, with **mandatory developmental surveillance by health visitors at 2 years.**
- **US CDC "Learn the Signs. Act Early"** – universal public health model, empowering parents and professionals to flag concerns early.
- **Canada's "Ontario Autism Program"** – provides **free diagnostic assessments** and **care navigators** who guide family's post-diagnosis. This supports caregiver-mediated early years supports.
- **Finland** – integrated **multi-agency child health/ child development clinics** that offer on-site assessment and integrated health, education and therapy services at no cost.

Appendix 7: After-School Care (OSCH) Integration

Co-located and Inclusive Community Programs:
Based on Canadian and Nordic models, ideally, after-school programs should operate on school sites, **co-delivered by trained educators and/or disability inclusion staff.**

After-school care models should also be considered for an overhaul where they become more in line with **community-led, peer-connected programs** operated from the school site.

Funding Structures:

Given the funding challenges for after-school care due to:

1. inconsistent and unstable funding, as funding is usually based on how many children are in attendance, or short-term grants.
2. higher staff ratios and expertise (trained educators/ disability inclusion staff) to support children with developmental delays or disability; and
3. families not being able to afford higher fees

different funding models need to be examined.

A potential model to balance **affordability for families** and **financial viability** for providers is to:

a) fund community-led peer connected programs, with a trained educators or disability inclusion staff present.
b) change to a program that is more appealing to children universally but at a level that engages children with disability to increase numbers, such as bowling, tag games, computer games, simple sporting activities like self-defence.
c) move the administrative burden to the school/ education department; and
d) innovative funding models such as:
    - **Cost Plus where the “Plus” is Outcome Performance Based:**
        - Cost = Block Funding to cover reasonable overhead costs (which is subject to open book audits). This is effectively the fixed costs that exist regardless of how many children attend. The open book is to check that the costs are reasonable.
        - Plus - the variable costs which are the per-child costs. This is **outcome-based performance** linked to participation, confidence, and skill-building, and not hours.
    - Additional staffing could be provided through place-based final year allied health students
    - The funding becomes part of the school’s obligation

If the government is concerned that there is too much risk, and that costs are not going to be managed despite the open book requirement, or supports are not incentivised to undertake quality programs make the “plus” the basis of an “alliance outcome-based performance contract” where there is risk/ reward sharing between government and the program provider be that the school, community or private provider.