Masking is not thriving: Views of children and young people with disability, parents and caregivers on Thriving Kids

Summary of survey responses
collected September 2025

December 2025

Children and Young People
with Disability Australia

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A note on language:

In this report, we use person-first and identity-first language. Person first language includes “person with disability”, and identity first language includes “disabled person.”

Acknowledgements:

We would like to acknowledge the Traditional Custodians of the Lands on which this report has been developed, whose cultures and customs have nurtured and continue to nurture this Land since the Dreamtime. We pay our respects to their Elders past and present. This is, was and always will be, Aboriginal Land.

Thanks:

CYDA acknowledges the experiences of children and young people with disability, their parents and caregivers, and appreciates their time to complete this survey. Their voices and perspectives are at the heart of CYDA’s advocacy to government.

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Content warning: This report references systemic neglect, discrimination, ableism, abuse and suicide.

Background

The Australian government’s Thriving Kids program was announced by Disability Minister Mark Butler on 20 August 2025.[1]

Thriving Kids will be a supports system for children with developmental delay and autism under nine years old, as a targeted alternative to the National Disability Insurance Scheme (NDIS). It will launch in July 2026, with access changes to the NDIS commencing from mid-2027.

The government says that Thriving Kids will focus on identifying developmental concerns earlier, by establishing a national system of supports for children with “low to moderate” developmental delay and disability, and their families. Children with “permanent and significant” disability will continue to be supported through the NDIS.

According to the federal Department of Disability, Health and Ageing, there will be a $2 billion commitment over five years towards Thriving Kids, from 1 July 2026. This funding is expected to be matched by state and territory governments, although the timeline and process is yet to be confirmed.

CYDA is part of an Advisory Group co-chaired by Minister Butler and Professor Frank Oberklaid, that is providing strategic advice about the Thriving Kids program. The group includes experts in children’s development and advocacy groups. They are meeting regularly, including holding deep dive sessions with representatives on other peak and advocacy groups. The Advisory Group’s advice to the government is expected to be finalised by December 2025.

The Advisory Group are informed by their internal expertise as well as by the findings of the Parliamentary Inquiry into the Thriving Kids Initiative by the House Standing Committee on Health, Aged Care and Disability. Within a short submission timeframe, the Inquiry received 335 submissions, including 39 from individuals, and 267 from organisations.[2]

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[1] See https://www.health.gov.au/ministers/the-hon-mark-butler-mp/media/speech-from-minister-butler-national-press-club-20-august-2025?language=en.

[2] See https://www.aph.gov.au/Parliamentary_Business/Committees/House/Health_Aged_Care_and_Disability/ThrivingKidsinitiative

Introduction

Children and Young People with Disability Australia (CYDA) is the national representative organisation for children and young people with disability aged 0 to 25 years. CYDA values the lived experience of the community as a basis for driving systemic change and advocating for system reform that meets the needs of children and young people with disability.

On 27 August 2025, just one week after Minister Butler's announcement and in response to our community expressing the need for a channel for feedback, **CYDA launched a survey to gather views about the Thriving Kids initiative** from children and young people with disability, their parents and caregivers.

Survey questions were intentionally designed to provide our disability community with the **opportunity to shape Thriving Kids by expressing what supports they use, need, and would like to see included,** and to highlight **key system risks** such as continuity, co-design, access burden, workforce and cost.

Who responded to the survey?

Over 15 days, 1535 responses were received from across Australia.

To focus on the user group for Thriving Kids, this Report is based on analysis of the **1235 responses** received from **children and young people, their parents and primary caregivers.**[3] We included children and young people aged 0–25 who completed the survey themselves.

91 per cent of the 1235 responses were **parents and caregivers of children and young people with disabilit**y.[4] Of these parent/caregiver responses:

- **91 per cent** reported that the child or young person they cared for was an **NDIS participant or applicant**.

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[3] We did not include the 300 responses from those who were not parents, primary caregivers, or children and young people with disability. "Other" responses were included where people clearly identified as (a) parents/carers with disability and (b) parents who also work in disability-adjacent roles.

[4] Note: We did not include "Other" survey participants where their primary role was not the core caregiver, such as: kinship and grandparent carers (part-time guardianship or informal care), respite foster/Out-of-Home carers, support workers/therapists/plan managers/teachers, or "transition edge" supports (parents of young adults over 25 who still provide substantial care). These groups show where standard categories can miss care constellations and where future forms should explicitly recognise kinship/foster/grandparent carers and blended roles.

- **62 per cent** of parents/caregivers were caring for a child **aged 0–9 years**, with the remainder spread across the age groups 10–14 (24 per cent), 15–17 (eight per cent) and 18–25 years (six per cent).[5]
- The most common diagnoses among the children and young people they cared for were **Autism (81 per cent)** and **ADHD (60 per cent)**.
- Disability was frequently **co-occuring**, with **72 per cent** of those with Autism reporting a co-occurring condition, including ADHD, psychosocial/mental health, learning difficulty and other developmental/neurological conditions.
- Parents and caregivers most often reported caring for **boys** (64 per cent), followed by **girls** (30 per cent), then **gender-diverse children** (non-binary/other, five per cent).

Two per cent of the 1235 survey participants were children and young people with disability **aged 0-25 years.** For these participants, **100 per cent were Autistic,** co-occurrence was common (for example, with ADHD and mental health conditions), and most participants identified as a girl or woman.[6]

24 per cent of survey participants lived in **New South Wales, 24 per cent** in **Victoria**, 19 per cent in Queensland, 15 per cent in Western Australia, 13 per cent in South Australia, four per cent in Tasmania, two per cent in the Australian Capital Territory, and one per cent in the Northern Territory.

Using postcode-to-remoteness mapping, **22 per cent** (274 responses) of parent/caregiver participants were identified as **non-metropolitan**.[7] These responses indicated that despite clear clinical need, regional families encountered **major barriers**, including limited provider options and increased travel costs. There were strong calls for **telehealth and outreach**, **regionally weighted commissioning**, and **“no worse off”** protections.

Seven per cent (88 responses) were parents/caregivers of children and young people who were **LGBTIQA+**. They were more **likely to be regional/remote-based**, compared with overall participants (32 per cent compared with 22 per cent). Among

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[5] Note: The survey was designed before it was made clear that Thriving Kids would focus only on children aged 8 and under. Hence, our survey sample refers to children 9 and under as this corresponds to the age categories we used.

[6] 16 participants identified as a girl or woman, one as a man, four as non-binary, two selected “prefer not to say,” and three did not provide a response.

[7] Using the Australian Statistical Geography Standard and the Accessibility/Remoteness Index of Australia, we define *non-metropolitan* areas as all regions classified as Inner Regional, Outer Regional, Remote, or Very Remote (coded as RA2–RA5), i.e., everything outside Major Cities (RA1).

this group, there were more **gender-diverse** children, who needed support from a **team** of people with **different skills** working together to deliver **relationship-centred** supports. Over half foresaw that their support needs would be **lifelong**.

Seven per cent (87 responses) were parents and caregivers of children and young people from **multicultural backgrounds.** Their responses identified pronounced needs for **language access**, **cultural safety**, and **navigation support**.

Six per cent (77 responses) were parents and caregivers of **First Nations children and young people.** Co-occurrence of Autism and ADHD was high among the children and young people they cared for, at 62 per cent (compared with 60 per cent of overall responses). They were more than **twice as likely to be regional/remote-based**, compared with overall participants (47 per cent compared with 22 per cent). Their responses reflected a strong preference for **continuity and guarantees** throughout the design, rollout, and implementation of Thriving Kids.

The design implication of these diverse responses is that **Thriving Kids cannot be framed for "not complex."** Responses show multi-condition, multi-support needs—especially where Autism and developmental delay co-exist. Program, workforce, and funding must start from this complexity baseline, including mixed settings, continuity of clinicians, and clear pathways.

Report structure

The report is structured in **three main parts:**

Part 1: Key messages for government, where we present CYDA's **headline recommendations** for Thriving Kids based on survey responses.

Part 2: Key issues, where we provide detail about the main concerns that survey participants shared about Thriving Kids across five areas:

a. Falling through the cracks of the support ecosystem
b. One-size-fits-all as ill fitting cost cutting
c. Rushed rollout erodes co-design and community trust
d. Ableist, behavioural framing as uninformed and unjust
e. The weight of system failures: distress, trauma and fatigue

Part 3: Suggestions for improvements, where we highlight the key suggestions that survey participants raised for Thriving Kids across eight areas:

a. Guiding principles for delivering the Thriving Kids initiative
b. Co-designed and evidence-based supports, governance, and evaluation
c. Systems-level coordination and no wrong door
d. Build on existing supports that are still needed
e. Provide holistic, relational supports
f. Ensure equitable resourcing and capacity building
g. Tailor supports across age cohorts
h. Tailor supports to diverse and intersectional needs.

How to read this report

Percentages are calculated based on the number of responses to individual questions, unless otherwise specified.

Direct quotes from participants are indented, italicised, and in inverted commas, anonymised to protect privacy, and minimally modified for brevity and/or clarity.

Thematic analysis was used to analyse open-ended responses. Qualitative responses were coded and then grouped into broader themes and refined through a peer review process that checked for accuracy. This process has led to a coherent and meaningful account of participant lived experiences presented in this report.

More detailed breakdown of demographics can be provided on request.

Next steps

This survey is part of CYDA's ongoing commitment to understand how children and young people with disability, and their families and caregivers, experience reform in the sector.

CYDA presented the initial survey results directly to the **Parliamentary Inquiry into the Thriving Kids Initiative**, as part of a submission endorsed by 15 disability and peak organisations.[8]

CYDA is a member of the government's **Thriving Kids Advisory Group,** and will share this report with the Advisory Group prior to its final meeting on 9 December 2025. Informed by the survey responses, CYDA is campaigning to make sure the program will work to meet the needs of children and young people with disability, their families and caregivers.

CYDA also keeps confidential records of social media comments, calls, and emails received about Thriving Kids, and shares anonymised findings from these with the wider community when relevant. CYDA will continue to keep our community updated on Thriving Kids as it progresses.

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[8] See Submissions – Parliament of Australia.

Key findings

- **1235 responses** from parents, caregivers, children and young people with disability. Ninety-one per cent were parents and caregivers, and two per cent were children and young people. There was high prevalence of Autism (81 per cent), ADHD (62 per cent), and co-occuring conditions. There was geographic spread across Australia, with high response rates from regional and remote participants (22 per cent) and diverse groups (seven per cent LGBTIQA+, seven per cent multicultural, six per cent First Nations). There was higher prevalence of Autism in regional and diverse groups. LGBTIQA+ and First Nations participants were more likely to be regional/remote-based.

- **Design implication of diverse responses:** Thriving Kids cannot be framed for “not complex.” Responses show multi-condition, multi-support needs—especially where Autism and developmental delay co-exist. Program, workforce, and funding must start from this complexity baseline, including mixed settings, continuity of clinicians, and clear pathways.

- **Emotional burden:** Three-quarters of survey participants reported feeling worried about Thriving Kids, and around half scared or confused.

- **Key issues:** Participants pointed to falling through the cracks between systems, Thriving Kids as a cost cutting measure, limited information and short timelines that do not allow for genuine co-design, fears of losing choice/control and continuity of trusted clinicians, and the negative impacts of ableist language, system trauma, and fatigue.

- **Suggestions for improvements:** Survey responses were highly constructive. Families and children are not rejecting mainstream delivery, they are pointing to how to make it ethical and effective. Survey participants specified the components of guiding principles to underpin Thriving Kids including affordable neuro-affirming supports, choice and control, co-designed process from design to governance to evaluation, systems level coordination, building on existing trusted supports, relational supports, equitable resourcing and capacity building, and tailored supports for age cohorts and diverse/intersectional needs.

- **Key messages for government:** Based on survey responses, CYDA is calling for the government to:

1. Coordinate a systems-level response guaranteeing supports to all children who need them
2. Co-design, pilot, and evaluate with the user group
3. Design and invest in equity of access
4. Provide tailored, holistic, and neuro-affirming practices and messaging
5. Build trust and accountability through oversight

Part 1: Key messages for government

CYDA's five recommendations for Thriving Kids based on survey responses are:

1. Coordinate a systems-level response guaranteeing supports to all children who need them

Thriving Kids must complement NDIS support, not replace it. This entails integrating and aligning the broader disability support ecosystem to provide "no wrong door" supports, low administrative burden, and continuity across ages, settings and transition points. The government should guarantee that any child removed from the NDIS is no worse off and can still access the supports they require.

2. Co-design, pilot, and evaluate with the user group

Co-design the program with deep input from the parents, caregivers, children and young people with lived experience of disability who will use it. This involves building on evidence of what supports already work, transparent co-design, governance, trialing new models and frameworks, and evaluation.

3. Design and invest in equity of access

Provide a support eco-system that aligns with the diversity of lived experience in the user group, not one based on bureaucratic convenience. The community clearly indicates the need for service models underpinned by principles of equity. Challenges in regional and remote areas should be prioritised along with diverse access needs of First Nations, LGBTIQA+, and multicultural communities.

4. Provide tailored, holistic, and neuro-affirming practices and messaging

Ensure trauma-informed, neuro-affirming practice, choice and control, and use communication standards that consistently emphasise strengths rather than deficits. Existing protective relationships and supports must be able to be maintained. The community strongly rejects behaviourist-based services such as Applied Behaviour Therapy, ableist concepts like 'mild' and 'moderate', and block funding for one-size fits all programs, preferring flexible supports across mixed delivery settings.

5. Build trust and accountability through oversight

Implement an independent oversight body including an advisory group of users with lived experience of disability. This will address the high level of distress and distrust in Thriving Kids demonstrated by survey participants. Models for evaluation should be determined early, and equity and inclusion must be centred in design, delivery, and evaluation of the funded supports and the outcomes they are achieving.

Part 2: Key issues

Survey participants were asked:

- how they felt about Thriving Kids and why
- what supports it should and should not include
- what supports they currently accessed through NDIS, and would continue to need to access
- if the amount of time to launch Thriving Kids was sufficient, and
- any other views they wanted to share on Thriving Kids.

Across their responses, participants highlighted a number of headline concerns with the Thriving Kids Initiative. We present these under five key headings below.

a. Falling through the cracks of the support ecosystem

A standout issue was the concern that children would **fall through the cracks** between supports systems and programs.

This issue was mentioned in 579 instances by survey participants, who were worried about the overlap and mismatch between NDIS and Thriving Kids, as well as the existing and potential gaps in services because of waitlists and difficulties accessing supports.

Eleven per cent (55 responses) highlighted the **inefficiency** of creating two overlapping bureaucracies. Especially for those with multiple diagnoses (autism and hearing loss, or ADHD and intellectual disability), this was seen to potentially lead to:

> *“double paperwork, double meetings, half the support.”*

There was fear that Thriving Kids was being used to **replace, rather than complement**, NDIS and other disability supports for children within the program’s age target.

There was a high level of concern about **loss of supports** (29 per cent of responses) for these children in the process of transitioning to the new initiative.

This was especially due to the perceived inability of the proposed mainstream delivery channels, such as schools, to meet tailored and complex needs.

> *“If the plan is to bring supports into the school environment, it is pretty much guaranteed the ones who need it most will slip through the cracks.”*

If needs were not met, there was concern that the responsibility for ensuring adequate provision of supports would be **absorbed by families**:

> *“More kids are going to fall through cracks adding even more strain onto families that are already struggling.”*

There were also striking levels of concern from the 38 per cent of survey participants who were parents and caregivers of **children and young people over the Thriving Kids age threshold**.

They felt that while it was unclear how Thriving Kids would work alongside the NDIS, at least it provided some pathway for children within the age target. On the other hand, the **future for older children was left in limbo**. Families felt abandoned, unsure if they were still guaranteed support from the disability ecosystem, and if so through which funding and delivery channels—NDIS or otherwise.

This concern was exacerbated by the clear pattern in responses relating to **unmet needs** in supports for older children, illustrating that while early-childhood NDIS pathways provide structured therapeutic support, supports in adolescence and young adulthood are characterised by **service contraction** and **fragmented access** to relational or transitional programs.

> *“Incredibly disappointed and have lost faith in the government's ability to care for the disability community. Using the terms mild to moderate autism which are completely unfounded, leads me to believe that this program will be nothing more than a publicity stunt to hide kicking thousands of disabled people from the NDIS.”*

> *“I am nervous that this is foreshadowing funding cuts and myself and people like me no longer being able to access the NDIS and thus the supports we need to actually thrive.”*

b. One-size-fits-all as ill fitting cost-cutting

Participants were consistently concerned that Thriving Kids represented **cost-cutting or shifting**, rather than an investment in positive outcomes for children with disability and their families and care communities.

> *"The government is using autistic children to save money; Autism is for life not just a childhood disability."*

Of the 310 participants who mentioned funding and resource allocation:

- 30 per cent (94 responses) explicitly framed Thriving Kids as **cost containment**
- 25 per cent (78 responses) predicted there would be **gap or out-of-pocket fees** for supports, and

- 21 per cent (64 responses) cautioned that **block-funded** supports would **replace individualised supports**.

> *"You'll still pay the therapists—just through another broken system."*

The impacts of this cost-shifting exercise were seen as profound and harmful, **exacerbating existing NDIS service gaps** and leading to **less individualised supports**.

Some were concerned about lack of fairness in the current system (NDIS):

> *"Minimal consistency in NDIA reviews and plans is problematic at present - depending on who does the plan, seem subjective to how they file for what is 'appropriate' for any given child; often NDIA plan managers don't appear to be versed in the developmental assessments in NDIS Review Reports from the child's treating clinicians - this should be an allied health team reviewing client data to make decisions on developmental function of a child."*

Other existing issues they communicated included:

- long waitlists and administrative burden making access to supports difficult (78 responses)
- navigation difficulties, distance, and limited providers outside cities driving inequity of service provision in regional and remote areas (30 responses)
- need for navigators/advocates to support them to access a complex system.

Instead of providing a solution, they flagged that Thriving Kids would simply make things worse. Thriving Kids was seen to add to these issues by **shifting supports into mainstream settings lacking capacity** to provide disability and neuro-affirming care, or person-centred, flexible, and tailored supports.

In doing so, **Thriving Kids risks weakening the hard-won trust and continuity** that families have created with their existing supports and therapists.

In particular, 310 participants **did not trust that schools were set up** to deliver Thriving Kids effectively. They described a **systems-level misfit** between what schools could realistically deliver, and what autistic and developmentally delayed children needed.

The dominant worry was that under-resourced schools could not take on therapeutic activities they were neither staffed nor trained to provide.

> *"Under-resourced schools can't absorb therapy workloads."*

Participants repeatedly linked this to **foreseeable harms**: longer waits, fragmented care, and the loss of trusted one-on-one therapy whose continuity has underpinned progress to date.

Participants also emphasised that the allied health sector was already strained, especially in non-metropolitan areas. Without adequate and fully funded provision alongside "no-gap" safeguards, any move to block-funded, school-centred supports would lead to **waiting lists** and **out-of-pocket costs.**

This anxiety was **amplified** among 13 per cent (41 responses) of participants who were **homeschoolers and "school can't" families**. They perceived a **school-based model** as a form of **exclusion**.

> *"I am terrified my undiagnosed daughter will be forced into a one-size fits all massively underfunded program that teaches autistic children to mask and be judged on outward expression of neurotypical conformity rather than actual support needs."*

Shifting from choice-based individualised supports to block one-size-fits-all supports was seen as taking away rights, choice, control, and continuity of care. Participants saw this as **gatekeeping support** from those with "less visible" needs.

Parents and caregivers also predicted **additional inequities** for regional families, single-parent households, multicultural communities, and children who mask.

By adding another pathway to an already confusing and under-serviced support ecosystem without clear information about how it would work with this existing system, Thriving Kids was seen to **add more chaos** to a sea of poorly planned reforms.

There was a feeling that Thriving Kids was being rushed through with a lack of planning, resourcing, workforce allocation, commissioning, and capacity building. Participants saw the announcement as a **budget-driven exercise** that would **reduce** intensity, individualisation, and continuity of care.

c. Rushed rollout erodes co-design and community trust

Many of the concerns expressed in the Thriving Kids survey reflect a common story we hear within our disability community, especially since the NDIS Review: **A lack of time for genuine and meaningful consultation and co-design**, and a feeling that the **community is not being listened to** as part of these reforms.

> *"token listening followed by pre-determined outcomes."*

Among those who answered the question, **79 per cent of participants felt that 12 months was not enough time** to launch Thriving Kids, 16 per cent were unsure, and only four per cent thought it was enough time.

> *"There is absolutely no way they can consult properly, co-design properly and develop a model, then train all of the teachers, childcare workers etc, in 10 months."*

> *"They are rushing to try and get something implemented and underway before their electoral term has ended to prove they did something, when all it's going to do is*

> *break families and cause so much distress to the families who need these services for the children this is affecting."*

132 responses indicated that **more time was needed for genuine consultation and co-design** with those who would be using the services.

Out of these responses, the top concerns were:

- rushed rollout (32 per cent)
- developing an **evidence base** for program integrity (27 per cent)
- lack of **lived experience governance and co-design** (19 per cent)
- inability to build **workforce capability and commissioning structures** within a year (14 per cent), and
- time pressure creating **poor quality, confused delivery,** and **weaker safeguards** (11 per cent).

There was a strong sentiment among participants that the government was **not listening** to the lived experience of the disability community.

Some survey participants also felt that it was **too soon make drastic changes to the** NDIS, as there had not yet been enough time to evaluate the effectiveness of the NDIS "early intervention approach":

> *"Most of the autistic kids who started on NDIS early intervention are still teenagers, so it is too early to say they were "overserviced" or that it wasn't the right approach."*

> *"The government needs to listen to the Autistic community and what I've heard implies they don't understand the first thing about Autism."*

The language used in the Thriving Kids announcement ("mild to moderate") was taken by the disability community to signal

> *"a total absence of autistic input."*

Participants interpreted the absence of co-design not as an administrative oversight but as a **social and moral injustice**—a failure to recognise autistic and disabled people as legitimate knowers of their own experience. Without this, families warned, Thriving Kids risks perpetuating the very paternalism the NDIS was meant to replace.

> *"How can we properly measure the efficacy of this program and its effect and impact in a group of people who notoriously mask to people please and who struggle with communication? It just feels very insidious."*

d. Ableist, behavioural framing as uninformed and unjust

Participants were concerned with the **lack of disability awareness** in the Thriving Kids announcement, and saw the use of **ableist phrases and concepts** as evidence that policy makers neither understand nor respect the experience of neurodivergence.

> *“They didn't even get their facts right on the diagnostic terminology, so how can they truly understand what's involved in living with it and how much impact this will have.”*

There were 427 mentions within responses that **rejected the government’s language** around Thriving Kids, especially the use of labels such as “mild to moderate.”

> *“Please fix up the language “mild to moderate”, “school refusal” etc. Probably start with a genuine introduction to what neuroaffirming practice truly means amongst those designing the program. PLEASE recruit and involve autistic and neurodivergent professionals to help design this program and LISTEN to their experiences and what approaches and systems they have found to make meaningful differences.”*

Hundreds of responses described the label as scientifically inaccurate, morally offensive, and socially dangerous. They did not see it as a helpful description but rather as a **weapon that erases** the complexity and permanence of autism and as political shorthand for “**less deserving.**”

Participants called the label “ignorant,” “ableist,” and “medically illiterate.” They noted that autism is categorised in the **DSM-5 by support levels (1–3),** not by degrees of severity, and that **“mild/moderate” dismisses complexity** and allows for **gatekeeping.**

> *“Why are they using non neuroaffirming language and describing Autism in ways that isn't even diagnosed (mild/moderate etc) clearly this has been discussed and decided on by people who have zero clue about Autism, and how much it affects people differently and in different parts of their lives.”*

> *“We lost our neurodivergent son considered 'high functioning' by suicide. . . it is critical that those with mild to moderate 'impairment' are better understood and appropriately supported - Thriving Kids represents an opportunity to do so but without the stories of many being heard including that of our son, I feel it unlikely it will achieve this”.*

Participants expressed high anxiety that this shift in language was a first step in **stripping rights and NDIS eligibility** from children labelled “mild”, regardless of their functional needs and context. Parents described the years of advocacy required to get accurate assessments, and their worry that those efforts would be undone. Several recounted being “cut off at age six” or forced to re-prove disability after minor progress.

The government’s move from “lifelong disability” to “temporary condition” was interpreted as the first step toward **systematic exclusion**. There was some concern that this was attached to the medical model of disability, potentially amplified by shifting the disability portfolio into the federal Department of Health:

> *"Need to avoid returning to a medical model and pathologising disability. Children should be supported by early childhood early intervention specialists to engage in mainstream services. Parents should be supported through the early years to build confidence and engagement."*

Underpinned by current diagnostic tools and evidence, participants described **autism as lifelong and variable**, and not a condition one “grows out of.” They emphasised fluctuating capacities—children who mask distress at school but revert at home, or adults who require more support as social demands increase.

One participant called for alignment with the National Autism Strategy, which was underpinned by extensive consultation with the Autistic community:

> *“Policy must adopt a neurodiversity-affirming lens, in line with the National Autism Strategy and the voices of Australia’s Autistic and autism community to avoid pathologising autism .... Whatever systems Autistic children and adults have access to need to take a holistic and systemic approach, as autism is a life-long neurodevelopmental disability. Support needs may be ongoing, fluctuating, and context-dependent as reflected in the National Autism Strategy. Over 95 per cent of Autistic people have a co-occurring disability and/ or medical or mental health condition and/or face multiple and overlapping forms of disadvantage and discrimination due to intersectional identities. Without explicit protections, broad programs risk compounding inequity as outlined in the Senate Inquiry on Autism report”.*

Participants pointed out that the language of “mild/moderate” **denies fluctuation in support needs**, which deepens the stereotype that intelligence or the ability to speak is equal to not needing support. Parents of high-masking children emphasised that invisibility does not mean absence of need.

> *“The usage of non clinical terms such as mild and moderate autism is so belittling to my daughters experience. Autism is a dynamic disability.”*

> *“There's no such thing as mild autism. All individuals with autism can have low and high support needs depending on the moment, day, week or season that they're in.”*

In practice, participants suggested that Thriving Kids would likely emphasise behavioural interventions designed to **assimilate autistic children** into the mainstream, which is incompatible with neuro-affirming evidence and practice. They expressed fear about a focus on correcting behaviours and encouraging masking, leading to **trauma and burnout for children**.

> *“I don’t want my child to attend aba/compliance based therapies, groups etc. I don’t want her disability to be “trained out of her” or encourage masking.”*

In 189 instances, responses explicitly rejected **Applied Behaviour Analysis (ABA)** and related compliance-based or “masking” therapies. ABA was denounced as **harmful, unethical, outdated, and incompatible with neuro-affirming practice**.

> *“Inklings, aba. Because it's 2025 and we don't do dog training for children. We know the long term impacts masking has on mental health and well-being for autistic people”.*

> *“ABA - Do not try to force autistic people to behave as though they're not autistic. It is dehumanising, and traumatising. We're different, not inferior.”*

Along with the clear link to well-established wellbeing outcomes, participants also qualified their opposition by drawing links to political and program drivers. They felt that behavioural programs would **prioritise fast improvements** to meet funding requirements rather than children’s needs.

> *“Scared that the only option most will end up offered is some form of aba because the systems which are funded will have KPIs which demand fast improvements”*

119 participants expressed that neuro-affirming, individualised therapy, and continuity of care is a **fundamental right**, not a ‘nice to have’. Parents and carers linked the use of “mild/moderate” labels and behaviourist models to a **broader withdrawal of rights** and shift toward **welfare framing**, with further **inequities** for those already disadvantaged (regional families, single parents, multicultural communities, high masking children).

For our community, **choice and dignity are inseparable from justice**. Language that minimises need and programs that normalise compliance are seen as **human rights regressions**, not neutral policy settings.

> *“A compliant child is not a regulated child.”*

e. The weight of system failures: distress, trauma and fatigue

The level of distress described in response to the details of Thriving Kids cannot be overstated.

Participants described feeling **worried** (76 per cent), **scared** (51 per cent), and **confused** (51 per cent) by the proposed initiative. Only 12 per cent were interested, five per cent neutral, four per cent positive, and two per cent excited.

Within the 15 per cent who selected ‘other’ and used the open-text box to specify emotions, they most frequently described **anger (26 per cent)**, **frustration (six per**

cent), disappointment (five per cent), and **stress (four per cent)**, alongside mentions of feeling **powerless, suspicious, abandoned**, and in a few cases **suicidal**.[9]

> *"The way the government announced this program was so distressing. By blindsiding the community, it has set a really negative tone of anxiety, confusion, distrust and disrespect. Consultation and a transparent commitment to true co-design are desperately needed in order to create a fit for purpose program."*

Around 15 responses described **severe distress** such as sleeplessness, panic attacks, and despair, feeling "the rug pulled out," and being "sick to my stomach."

For many, this was compounded by memories of earlier **systemic neglect**, producing a **collective trauma narrative** linking this policy change to people's sense of safety.

> *"Outraged, sickened, furious and heartbroken."*

When asked why they felt this way, 1143 participants shared concerns reflected elsewhere across this report about:

- lack of detailed information and rushed timeline
- problematic descriptions of autism and disability from government which risk a backwards step to outdated non-neuroaffirming understandings and approaches to disability
- block-funded supports that are not individualised
- insufficient capacity and equity to deliver in schools
- increased emotional, mental health, and financial burden on families.

Participants described their **trauma from navigating a support ecosystem** already defined by scarcity, where trust has been repeatedly breached and where every announcement is interpreted in the context of prior disappointments.

> *"NDIA have eroded any trust I have in government services."*

The rhetoric of "Thriving Kids" is experienced as a promise of 'thriving' but delivered through systems that people associate with trauma and loss.

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[9] Sometimes these feelings could co-occur in responses.

The result is a **collective exhaustion** for parents and caregivers who have had to become experts in bureaucracy, advocacy, and the limitations of a system designed by policy makers who did not properly consult them.

> *“For a single parent who is struggling to care for her autistic children this has put huge anxiety on top of an already stressful situation. I have one child on the verge of needing out of home care which is heartbreaking for us all and shouldn’t happen with the correct supports. Childrens’ future is at stake. Stability is so important.”*

> *“I’m already struggling with NDIS, having to learn to navigate a totally new system feels overwhelming”.*

Parents were concerned that Thriving Kids might **shift more responsibility onto families** while offering less tailored support, especially via generic parenting programs that were frequently described as not helpful for the unique needs of their children.

> *“NOT MORE TRAINING - I am exhausted and time poor, everytime I reach out for help from CarersGateway that's what I get offered. I understand what is happening, and I know what I need to do to cope, I just don't have the resources to cope. It is deficits based and messages that I need to be 'fixed', it is the antithesis of trauma informed practice.”*

Parents were also concerned that financial and administrative responsibility would be shifted to them. One parent said supports should,

> *“be fully-funded, just as NDIS supports are - there is already a significant cost-burden of having a disability without shifting therapy supports back to parents.”*

Part 3: Suggestions for improvements

Survey participants had many constructive ideas for ensuring the Thriving Kids initiative could be effective and supportive, highlighting what existing supports they found useful and what supports they would like to see included. Several ideas were also in response to some of the key concerns they raised.

Families and children are not rejecting mainstream delivery: they are **specifying the conditions** that make it **ethical and effective**. They suggested **long-term thinking about investment**, such as early, tailored support, would avoid cost at a later date into adolescence and adulthood.

Across their responses, participants highlighted a number of suggestions for improving Thriving Kids. We present these under eights key headings below.

a. Guiding principles for delivering the Thriving Kids initiative

The following guiding principles have been developed from survey responses to questions that asked what components an ideal Thriving Kids program would include:

1. Tailored and continuous support

Every child's journey is unique. Supports are tailored to each child's strengths, needs, context, and developmental stage, while ensuring continuity and stability over time. Thriving Kids adapts as the child grows, providing consistent relationships, smooth transitions, and sustained support into the future. Families can plan with confidence, knowing that Thriving Kids evolves alongside their child.[10]

2. Neuro-affirming and trauma-informed practice

Thriving Kids recognises and celebrates diversity while promoting safety, trust, and emotional wellbeing. It adopts strengths-based, neuro-affirming, and trauma-informed approaches that honour each child's identity and experiences, and does not reward or support masking or compliance.[11]

3. Choice, voice, and control

Children and their families are empowered to make meaningful choices about supports, goals, and how services are delivered (providers, setting, and timing).

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[10] Based on 86 per cent of responses that wanted Thriving Kids to be "Tailored to individual needs" and 76 per cent of responses that wanted "Guaranteed support into the future."

[11] Based on 79 per cent of responses that wanted Thriving Kids to be "Neuro-affirming" and 65 per cent that wanted Thriving Kids to be "Trauma-informed."

Decision-making is shared, recognising the importance of both children's voices and the lived expertise of families.[12]

4. Maintain and strengthen what works

Effective and trusted existing supports are retained or integrated to ensure continuity of care. Coordination is built in to provide stability and avoid dismantling or duplication.[13]

5. Flexible and mixed delivery settings

Services are delivered in flexible and accessible ways that fit each family's routines, local context, and sensory profiles — whether in homes, early learning settings, or community spaces. Supports are embedded in everyday environments, helping children connect with peers, neighbourhoods, and their communities. Delivery settings include a mix of home, clinic, school, community, and telehealth.[14]

6. Person-centred and family-oriented

Each child is supported as a whole person, within the context of their family and community. Families are recognised as partners and experts in their child's life and wellbeing. Family capacity and peer help are funded.[15]

7. Affordable and equitable

Services are financially accessible, transparent, and equitably distributed, ensuring inclusion for all families. Cost is removed as a barrier and access is guaranteed. Targeted equity measures are introduced, such as regionally weighted commissioning and outreach.[16]

8. Coordinated, low-burden access

Processes are streamlined to reduce stress on families and maximise time spent supporting children. There is a coordinated approach to provision including "no wrong door", clear division of roles between sectors and programs, less paperwork, funded navigation, and clear communication.[17]

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[12] Based on 76 per cent of responses that wanted Thriving Kids to preserve "Choice and control", 33 per cent that wanted it to be "Led by children", and 33 per cent "Led by parents."

[13] Based on 72 per cent of responses that wanted Thriving Kids to "Maintain some existing supports."

[14] Based on 71 per cent of responses that wanted Thriving Kids to include "Flexible delivery" 53 per cent that wanted it to be "Local", 46 per cent "Based in everyday settings", and 39 per cent "Community-based."

[15] Based on 71 per cent of responses that wanted Thriving Kids to be "Person-centred" and 33 per cent "Led by parents."

[16] Based on 69 per cent of responses that wanted Thriving Kids to be "Affordable."

[17] Based on 52 per cent of responses that wanted Thriving Kids to be "Low administrative burden."

9. Rights-based foundation

Thriving Kids is grounded in the UN Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities, ensuring dignity, participation, and inclusion in all aspects of program design and delivery. Language and practice are strengths-based and rights-based, rather than deficit-based.[18]

10. Safeguards around language and delivery

Guardrails are installed to protect rights and supports:[19]

- No behavioural or compliance-based programs, including prohibition of restraint/seclusion and masking-focused practice.
- Assurance of continuity across transitions, retaining 1:1 intensives, and trusted clinicians. No forced provider changes or group-only default.
- Out-of-school access for homeschoolers and children experiencing "school can't".
- Replace "mild/moderate" labels with support needs, replace "school refusal" with "school can't".
- Increase affordability for core therapies where possible, travel loadings, and price transparency.
- Build in transparent governance through independent oversight and evaluation.
- Protect and support equity through regionally weighted commissioning, culturally safe supports, targeted outreach, and tailored supports.

b. Co-designed and evidence-based supports, governance, and evaluation

Even though responses revealed deep community alienation from policymaking, they also showed that our community retains a **strong collective understanding** of what **authentic participation** should entail.

The disability community principle of "**Nothing About Us Without Us**" needs to be applied in the spirit it was intended, not co-opted as a government tick boxing

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[18] Based on 49 per cent of responses that wanted Thriving Kids to be "Rights-based."

[19] The many open ended responses provided by survey participants also demonstrate the clear boundaries people want around the Thriving Kids program design and delivery.

exercise. The principle underscores that consultation must be embedded, transparent, and ongoing.

Across 138 responses, co-design was defined as a caring and deeply relational practice that cannot be rushed. It is a **time-intensive process** that builds trust, honours lived expertise, and prevents harm.

Responses displayed a clear sense of what was needed to **embed co-design and evidence,** and asked for:

- lived experience governance of Thriving Kids
- co-design with autistic-led organisations, especially to co-deliver teacher and education support for professional development
- co-designed supports and evaluation measures that consider the lived experience of a diverse set of groups
- a trial period and staged approach with pilots and evaluation prior to scaling up
- an independent body to ensure evaluation is credible and trusted.

> *“The program is not evidence based and not co-designed with families. Shouldn't we get a right to say what supports suit our children.”*
>
> *“Please co-design and guarantee no child is worse off.”*

c. Systems-level coordination and no wrong door

The majority of participants prioritised the idea of a **support guarantee** that would assure continuity across systems and the ability to maintain current supports.

Survey participants asked for multiple access points or a “no wrong door” approach, as well as coordinated support, with one plan and coordinator. This was to ensure that they had a streamlined, trusted, and consistent point of contact for navigating multiple complex systems simultaneously.

They also asked for clear and transparent **program boundaries** between Thriving Kids and the NDIS.

Many predicted conflict between federal and state systems, and urged integration rather than duplication. There was a desire for **effective, systems-level coordination** and clarity, leading to a **joined-up support ecosystem** where there was a clear division of roles and responsibilities.

> *“Thriving kids appears to be just another barrier to accessing support. From the problematic language of ‘mild to moderate’ autism to the uncertainty as to what it means for autistic teenagers and adults, I cannot help but feel frightened. NDIS*

> *supports are already extremely difficult to get, especially for low to moderate support needs autistic people, and confusing the system further will only do more harm than good."*

> *"...I hope children don't miss out or fall through the cracks when it's changed up. Give with one hand take with the other!"*

d. Build on existing supports that are still needed

Children and young people with disability depend on **trusting relationships and consistency** to feel safe and meet their therapeutic goals. The continuity of existing supports is critical to maintain the gains they have made via NDIS funding.

> *"Waiting years to get access to the support therapists is stressful enough and now families have to worry if they will be able to continue to have those supports."*

Participants explicitly asked to **keep or strengthen supports tailored to individual needs** (86 per cent). Seventy-six per cent wanted guaranteed and sustained support into the future. A further 76 per cent wanted choice and control over goals, providers, setting, and timing. Seventy-two per cent wanted to maintain some existing supports, and 71 per cent wanted flexible delivery across settings including local delivery (53 per cent) and everyday settings (46 per cent).

Parents and caregivers of younger children described a need for more **intensive therapies and early-intervention programs**, particularly speech therapy and occupational therapy. Many also highlighted the lack of parent/caregiver programs in existing NDIS plans, signalling a preference for **family-centred models** (parent coaching, navigation, peer support) rather than individual therapy silos.

When asked what **existing supports** they or the child/ren they cared for used through NDIS, responses most commonly included: occupational therapy, speech therapy, psychology, support workers, physiotherapy, and additional mentions of behavioural therapy/support, dietician, and food/feeding therapy.

Forty-eight per cent of NDIS participants used these supports weekly, 19 per cent fortnightly, and 15 per cent daily. Twelve per cent preferred a more flexible timeframe—so that frequency of use could be tailored to respond to changing or fluctuating needs (e.g., during transitions or periods of higher need such as flare-ups).

Forty-eight per cent of NDIS participants, their parents and caregivers said that they or their child/ren would need supports for their whole lifetime, and 24 per cent said the timeframe for needing supports was unknown. As one respondent explained,

> *"Autism is a dynamic disability and support needs may fluctuate over a lifetime."*

> *"My son has level 3 autism and needs to go to special school. He NEEDS the level of therapy he receives. He will never get married have a job or have children. He will require lifelong care."*

e. Provide holistic, relational supports

What participants value most is how supports are delivered. Beyond listing concrete services, families repeatedly emphasised that support must be **relational, whole-person and neuro-affirming** –not compliance-focused or deficit-framed. They want providers who know their child, protect trust and continuity, and work across settings.

Relationality across settings is a core part of success. Families wanted supports that work where life happens, across home, school, and community, and not just in clinic rooms (71 per cent wanted flexible delivery, 53 per cent local delivery, 46 per cent everyday settings, 39 per cent community-based). Peer and family contexts were further indicated as important by 13 per cent of participants that identified peer/friendship social programs, and 10 per cent who identified respite care and short breaks. In open-text responses, parents coaching and peer support that is neuro-affirming and not generic was frequently specified.

A program that enables **autonomy and continuity** was described as critical for program success by survey participants. Many families detailed the years of work required to build a team of trusted therapists who understand their child's sensory profile, anxiety triggers, and communication style. The idea of moving to block-funded, school-allocated or government-contracted providers was repeatedly framed as a threat to the wellbeing of children if it forced provider changes or reduced 1:1 intensity.

> *"Relationships are the therapy."*
>
> *"Young children do NOT want to sit in an unfamiliar office and spill their deepest and darkest to a stranger. They want conversation to come naturally whilst learning new skills, working with their hands and being interactive. Supports should be holistic inclusive of a whole family."*

969 participants identified "supports that Thriving Kids should include" in a multi-select question. These desired supports complement the **neuro-affirming delivery** described above:

- OT (Occupational Therapy) — 54 per cent (524 responses)
- Psychology/Counselling — 42 per cent (406 responses)
- Creative Arts/Animals/Sport — 19 per cent (184 responses)
- Speech Pathology — 14 per cent (137 responses)
- Peer groups/Friendship/Social — 13 per cent (128 responses)

Other suggestions included physio/exercise (11 per cent), respite (10 per cent), school supports (10 per cent), assistive technology (nine per cent), support worker/community access (five per cent), specialist education services delivered at home, and specialised out of school hours programs.

If we compare these ideal suggestions with the NDIS supports currently accessed by families and children, we find that **the desired Thriving Kids supports match actual usage patterns.**

Among the 983 participants who also accessed the NDIS, occupational therapy (79 per cent), psychology (44 per cent), speech therapy (28 per cent), and physio/exercise (21 per cent) were the most accessed. This indicates that therapy remains central, but the relational and context-responsive delivery is what determines whether therapy is safe and effective.

Families linked **forced provider changes to trauma and regression**, especially for children with Pathological Demand Avoidance (also known in the community as persistent drive for autonomy) or situational mutism, who depend on consistency to feel safe.

> *“my kids will loose vital people they have taken a long to time get to know they and trust them and actually help our children plus neuroaffirming”.*

> *“Worried about who will be offering services. Continuity and therapeutic relationships broken for a neurotype that needs consistency and for whom trust is vital.”*

There was a strong rejection of behavioural, compliance-based and masking-oriented programs, and a **clear call for neuro-affirming care**. The deeply nuanced and holistic understanding of their children’s disability support needs was evident in the preference for neuro-affirming practice (76 per cent) and trauma-informed supports (65 per cent) for an ideal Thriving Kids program.

Participants emphasised **relationship continuation and child-led goals** over standardised programs:

> *“There is already lacking support out in the community I'm scared about losing trusted therapists my child is comfortable with, ones who really advocate for the best for your child and work so well with them to help them develop, grow and feel safe.”*

They described **relationally safe therapies** as understanding children and young people deeply, and focused on helping them feel good about themselves, rather than trying to change who they are.

> *“Back when we started therapies for my son they were aimed at trying to make him present as neurotypical and it caused him major trauma, which even though we changed to neuroaffirming approaches about 5 years ago the trauma still exists.”*

> *“NDIS has been a life line for not just our son but our family. It has allowed us to access therapies where our son is respected for who he is while learning skills. His therapist have become part of our family and the appointments allow us to get out*

> *the house to a safe environment. It's the supports such as the trained reception team knowing who we are and interacting with each family as individuals in a way that works best for them, the smiles of solidarity in passing from the other parents and a space where my son can thrive with educated professionals helping him while I can relax and take a breath from the constant worry that is being a carer to a child with a life long disability."*

The preferred approach was a **solid foundation of trust built over time.**

f. Ensure equitable resourcing and capacity building

Survey participants were adamant that mainstream systems, especially schools, must be **properly resourced and re-designed** to deliver **neuro- and disability-affirming supports**, without simply shifting clinical workloads onto classroom teachers or costs onto families.

72 participants indicated **school capacity and readiness concerns**, explaining that schools need embedded expertise, not more paperwork. 41 participants were keen to ensure that home schoolers and "school can't" students would have access to out-of-school pathways by design.

> *"We need school can't supports, not 'refusal' programs."*

Participants drew a strong distinction between inclusion in schools, and therapy delivered by schools. Many endorsed co-location or in-school access **if it was delivered in addition to rather than replacing individualised supports**, suggesting the benefits of capacity building such as teacher coaching, embedded occupational therapists and speech pathologists in classrooms, or inclusion tied to curriculum goals.

Although there were concerns that increasing teacher responsibilities would lead to further professional shortages, participants did suggest that **investing in teacher training** is important.

One respondent who was also a teacher said it was important to embed **capacity building and resource uplift** so practice actually shifts, indicating that this means avoiding a "PD (Professional Development) day, then nothing changes" pattern.

There were concrete examples of how to **resource school ecosystems without adding to teacher workload**. Many participants were solutions-oriented, calling for:

- school-embedded occupational therapists and speech pathologists whose core remit is teacher coaching and environmental design, supported through teaching release time and in-class coaching
- funded tutoring and literacy support outside the NDIS and education coffers
- dedicated out-of-school pathways (home, community hubs, telehealth plus outreach) for homeschoolers and children excluded by current settings

- protected 1:1 intensives during key transitions (starting school, year changes, puberty, secondary school), and
- integrated allied health capacity in schools that is added not substituted

Families were highly supportive of **teacher coaching and embedded allied health** when additive, but opposed replacing 1:1 therapy:

Some, such as the following participant, also pointed to the current issue of using NDIS funds to train teachers to support their children.

> *"Teachers need a better education program for handling kids with disabilities I waste funding educating teachers on how to handle autistic children and how not to become part of the problem."*

Classroom aides and education support were identified as needing **upskilling**, with participants suggesting the commissioning of practical ongoing Professional Development for aides covering sensory regulation, Augmentative and Alternative Communication, demand-avoidance accommodations and "meltdown-prevention".

Many other participants were concerned about the way funding would operate and called for **stable multi-year funding** to avoid short pilots that fade out. 138 participants asked that before Thriving Kids is implemented, there should be a multi-year pilot, to then be scaled up after independent evaluation. This was frequently indicated as part of the principle of **long-term investment** hand-in-hand with early intervention, to reduce or displace costs in the future.

> *"They need to put as much early intervention in young people so when they become the working age they have developed those skills and can be employed and not need government benefits."*

Equity was highlighted in many responses that mentioned funding supports.

> *"It needs to be fully funded, no co-pay or Medicare partial rebates."*

> *"My beautiful child has big dreams but will need a lot of support in this period of his life so that he can achieve them. However, I have no doubt that he can become a voting, tax paying citizen in the future. However, under the Thriving Kids model he might not get the individualised and flexible support that he needs."*

In particular, rural and regional inequity surfaced across multiple areas including school resourcing (27 responses), service gaps/waitlists (38 responses), and NDIS overlap (33 responses). This indicates a need for regionally weighted commissioning, travel loadings, and directly employed clinicians to stabilise supply.

> *"In the country, the therapists don't exist to embed anywhere."*

g. Tailor supports across age cohorts

Although the Thriving Kids age target is early childhood (0–8 years), survey responses show that **needs continue and evolve** across childhood, adolescence, and young adulthood. Parents and caregivers want Thriving Kids to be designed as the **front end of a linked system**, with clear transfer to NDIS pathways, continuity guarantees, and participation funding so supports do not fall away after age nine.

What emerges across responses is that **age matters**: early childhood needs individualised foundational therapy plus family capacity-building, middle years need school-day adjustments and peer participation, teens and young adults need mental-health, transitions, life-skills, and employment supports. But all these **stages need to be linked** through explicit Thriving Kids to NDIS pathways, continuity guarantees, and participation funding.

Across age cohorts, families and caregivers repeatedly frame **thriving as belonging and doing**, not just receiving therapy. Preferences for flexible, local, everyday, and community-based delivery, and peer, creative/animal-assisted, respite and school-day adjustments, point to the need to **fund participation costs**.[20] This complements the overall “supports TK should include” list (occupational Ttherapy, psychology, creative/animal/sport, speech, peer/friendship/social, respite, assistive technology/ Augmentative and Alternative Communication), and **matches current NDIS use** across responses.

> *“My child has received life changing assistance from the NDIS. We privately paid for allied health services for 1 year and when my child was 3 we were able to access NDIS. The progress made was immeasurable and we are now at a mainstream school. While my child still needs and requires supports, I believe that early intervention greatly changed the trajectory of my child’s life.”*
>
> *“I taught for 25 years and still needed expert help to support my son. I was researching and training online and implementing a huge amount of strategies but my son needed specific support.”*

Below we present a breakdown of supports needs by age cohort, based on survey responses of parents and caregivers:

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[20] Costs include fees, equipment, uniforms, transport, support-worker accompaniment, AAC/AT consumables, and small flexible grants for hyper-local opportunities.

Young children 0–9 years (693 responses)

For the age range 0-9 years, **Thriving Kids should co-exist with NDIS** for children whose needs remain substantial, with mixed delivery settings and with explicit family-capacity components (coaching/peer) built in:

- Individualised requirements for foundational therapies and early intervention, with occupational therapy (41 per cent), speech pathology (26 per cent), and psychology (12 per cent) reported as the most important supports for this age range.
- Many noted the absence of integrated parent/caregiver programs in current plans and asked for family-centred models (parent coaching, navigation, peer support) rather than siloed, child-only therapy.
- Usage patterns in this age range speak to intensity and persistence of need among NDIS participants. Forty-eight per cent used supports weekly, 19 per cent fortnightly, and 15 per cent daily, with 12 per cent asking for flexible frequency to respond to fluctuating needs. Forty-eight per cent anticipated needing support for their whole lifetime and 24 per cent reported an unknown timeframe (dynamic needs).[21]
- These figures sit alongside preferences for tailored supports (86 per cent), guaranteed/sustained support (76 per cent), choice and control (76 per cent), and maintaining existing supports (72 per cent), signalling that continuity of trusted clinicians and 1:1 intensives must be protected through any transitions.

Middle childhood to early adolescence, 10–14 years (272 responses)

As children move into middle childhood and out of the Thriving Kids age target, they need **pathways to retain 1:1 intensives** where clinically indicated, and to receive **additive** school supports (teacher coaching, not workload transfer), with explicit **access routes outside school settings**:

- Needs shift toward school-day functioning—environmental adjustments, teacher coaching by embedded allied health, and tutoring/literacy alongside continued therapy.
- Families strongly preferred neuro-affirming and trauma-informed practice and rejected group-only substitution for individual therapy (explicitly cautioned in 29 responses).

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[21] Note: These percentages mirror the overall average percentages as this group makes up a large proportion (62 per cent) of survey responses.

- A distinctive pattern in this cohort was the emergence of “school can’t”; families need out-of-school pathways (home/community/tele-outreach) so access is not contingent on attendance (41 responses).
- These preferences aligned with strong signals around school capacity and readiness (72 responses) and teacher training (39 responses).

Later adolescence, 15–17 years (95 responses)

Later adolescence brings a need for **increased mental-health supports and participation funding**. Transitions are high pressure and high stakes, requiring wraparound support. There is a need to protect continuity and stepped intensity across milestones (new school year, exams), and explicitly fund participation so teens can belong and do, not only attend, therapy:

- Mental health needs compound due to anxiety and burnout after years of masking. This signals a need for executive-function coaching and support.
- High-stakes transitions in school include subject rotations and exams, and shifting into the workforce such as work experience and first jobs.
- Families and caregivers linked sustained outcomes to participation funding—fees, equipment, support-worker accompaniment, and transport—so teens can actually take part in sport, arts, and community programs.
- Without clear re-entry to NDIS-level supports where intensity remains necessary, progress stalls.

Young adulthood, 18–25 years (64 parent carer responses, 26 young adult responses = 90 responses)

For young adults, the focus shifts to **real-world participation**. There is a need for seamless NDIS continuity for ongoing needs, and to align Thriving Kids learnings with adult-service entry points, so gains made in early childhood translate into adult participation and thriving:

- In the 30 responses from young people with disability, co-occurring needs were common (notably ADHD and mental health). This contradicts any “low-complexity” framing, and underlines the need for complex supports.
- a focus on tertiary, TAFE and employment pathways, independent-living skills, driving/transport, and psychosocial supports.
- Support-worker hours for community access and mentoring often matter more than increasing clinic minutes.

h. Tailor supports to diverse and intersectional needs

Survey participants rejected one-size-fits-all models and called for **flexible, needs-based supports** that adjust to changing capacity over time.

> *"Strong preference for flexible, needs-based packages; resistance to generic block offers that underfit diverse needs and disrupt continuity."*

Across diverse groups, asks aligned with the guiding principles we outlined on page 23 of the report:

- neuro-affirming and trauma-informed practice
- continuity (no forced provider churn)
- choice and control with low administrative burden; and
- delivery across mixed settings (home, school, community).

Below, we highlight the intersectional experiences self-identified by participants, and key support needs for each group **in addition** to these shared features.

Autism prevalence and access concerns were amplified in four diverse groups of survey participants. The below rates of Autism prevalence are in comparison to **81 per cent of survey responses:**

- **LGBTIQA+ participants**: **95 per cent** Autism prevalence
- **Non-metropolitan** participants: **92 per cent** Autism prevalence
- **First Nations participants**: **91 per cent** Autism prevalence
- **Multicultural participants: 84 per cent** Autism prevalence.

Regional and remote-based participants (274 responses, or 22 per cent)

- Regional and remote-based participants were all parents and caregivers. There was high clinical intensity of need. Sixty-one per cent were supporting a child aged 0-9 years.
- Patterns of NDIS use mirrored overall responses, but **access barriers** dominated: thin local workforces, travel distances, cancellations, and higher out-of-pocket/travel costs.
- Families wanted to see regionally weighted commissioning, travel loadings, and direct employment of clinicians to **stabilise supply.**
- They wanted **school-embedded** clinicians to coach teachers while preserving **out-of-school options** for homeschoolers and those experiencing school can't.

- Levels of emotion (worried/scared/confused) matched or exceeded overall responses, driven by fears of being **left behind** if supports shifted to systems with limited local capacity.
- **No-worse-off guarantees** and continuity with trusted providers were non-negotiable.

“The government shouldn’t be making these decisions without consultation of community and families and caregivers. Every community is different, locality is different, services and supports are different. How will “Thriving Kids” serve remote communities?”

“Teachers try their best with good intentions but lack appropriate training and time to do what they need and want to do with crowded classrooms that are not sensory friendly. . . Adding more work onto them will see an even bigger exodus and more burnout”.

LGBTIQA+ participants (88 responses)

- About two-thirds of LGBTIQA+ participants were parents/caregivers (69 per cent); one in nine were disabled young people (11 per cent). A larger share lived **outside major cities** (32 per cent compared with 22 per cent of overall responses).
- Among parents/caregivers, most were supporting 10–14-year-olds, and **gender diversity among children was markedly higher** (30 per cent report identities outside “girl/boy”).
- Emotions were predominantly negative (worried 67 per cent, scared 51 per cent, confused 38 per cent), and **lifelong support expectations were higher** (53 per cent compared with 48 per cent of overall responses).
- Support demand was **broad and multidisciplinary**: allied health (occupational therapy/speech/physio/psychology all 83 per cent), plus peer networks (76 per cent), assistive technology (76 per cent), parenting programs (75 per cent), school can’t supports (73 per cent), and skills programs (72 per cent).
- **Program design** should explicitly combine neuro-affirming and gender-affirming practice, protect choice of clinician and privacy, ensure seamless transitions after the age threshold is reached, and address thin markets outside cities with telehealth/outreach and no-gap safeguards.

“The problem with the use of buzz words like rights based and trauma informed is that the likelihood the funded provider actually delivers rights based or trauma informed service is pretty low. If this is not driven by disabled young people, planned by disabled young people it's going to cause harm.”

“[Thriving Kids] undermines the hard-won rights of disabled children to individualised, flexible supports that recognise their diversity. Disabled people fought for decades to move away from welfare models that treated us as a homogenous group, and this feels like going backwards.”

Multicultural participants (87 responses)

- Multicultural participants were all parents and caregivers, and showed **lower connection to NDIS** (NDIS participant/applicant 84 per cent compared with 91 per cent overall).
- They placed much stronger emphasis on **language and cultural safety** than the broader group.
- Their policy asks appeared more frequently and more explicitly: **interpreters** funded at intake/planning/therapy/school meetings, translated and Easy Read/Easy English materials, time for interpretation within session caps, **bilingual/bicultural** clinicians and community connectors, provider directories tagged by language and clinician gender, privacy protections in small communities, and **co-delivered** Professional Development with **autistic-led and multicultural-led** organisations who were also audited for neuro-affirming and culturally responsive practice.
- **Support preferences** clustered at very high rates around speech and occupational therapy, psychology and parent programs (each over 80 per cent), plus out-of-school access for homeschoolers and children experiencing school can’t.

“I am very concerned especially for CALD communities… It’s a good idea in theory; however… true co-design would have occurred.”

“We already homeschool due to school trauma… If we lose allied health funding, our family will break down.”

First Nations participants (77 responses)

- First Nations parents and caregivers were spread nationally, but were more than **twice as likely to live outside major cities** (47 per cent non-metropolitan compared with 22 per cent of overall participants). This increases exposure to distance, workforce, and travel costs.
- Almost nine in ten children were **NDIS participants**, with 95 per cent NDIS participant/applicants combined (compared with 91 per cent of overall responses).
- **Disability profiles were more complex:** autism 91 per cent and ADHD 68 per cent (compared with 81 per cent and 60 per cent overall).

- Emotions were strongly negative: **“confused” was higher** (57 per cent compared with 51 per cent overall), reflecting uncertainty layered on systemic fatigue.

- Priorities concentrated on **continuity** (maintain existing supports 71 per cent, guarantee into the future 70 per cent) and **low burden access** (49 per cent), alongside strong endorsement of core allied health (occupational and speech therapy 92 per cent, psychology 86 per cent, physio 83 per cent) and whole family supports (parenting, respite, peer networks) plus school can’t responses (65 per cent).

- **The policy asks** were for regionally weighted, culturally safe, multi-year funding with embedded allied health across early childhood settings, homes, and community hubs—without forced provider churn.

"There are no details, no plan for states to provide, no provision discussed for education to assist. It seems like federal gov have decided our children are an easy target to get rid of instead of focusing on the real costs to NDIS. The millions spent on Administrative Review Tribunal fighting families who need support. Putting a payment scheme together that incentivises providers to charge for extras. An equivalent of a medical system for autism isn’t appropriate and feels like we’re returning to an age where we institutionalised neurodivergent individuals"

Comparisons across diverse groups

- **Continuity** was non-negotiable for all groups—but was **most urgent for First Nations** and **regional/remote** participants (higher early-childhood group, higher autism prevalence, higher exposure to non-metropolitan distance and workforce gaps).

- **Regional/remote** participants need **commissioned supports** that reflect distance and scarcity, with telehealth, outreach, and direct employment to stabilise access. School-based services must be **additive, not substitutes** for individual therapy.

- **LGBTIQA+** responses more often include **gender-diverse** children and anticipate **lifelong support**, strengthening the case for **gender-affirming + neuro-affirming** approaches, **seamless transitions**, and **broad, wrap-around** supports.

- **Multicultural** families and caregivers face additional **language and navigation burdens**, and call more often for interpreters, translated materials, bilingual clinicians, and community-based delivery with participation-cost coverage.

- **All the diverse groups** have deep lack of trust based on experiences with services, and require tailored continuity of care and trusted relationships with providers to thrive.

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