

Submission to the House of Representatives Inquiry into the Thriving Kids Program

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Executive Summary

This executive summary highlights the key challenges faced by families like mine raising autistic children, and the recommendations for the Thriving Kids Program to ensure children and families can genuinely thrive.

Key Problems

- ☐ Funding decreases as children's needs increase; restrictions on what funds can be used for.
- ☐ Exclusion of in-home supports and social/community participation (labelled 'parental responsibility').
- ☐ Severe workforce shortages in regional NSW; waitlists of 1–3 years for autism assessments and therapies.
- ☐ Plans and funding not updated regularly; children remain on outdated goals despite developmental changes.
- ☐ High levels of exclusion from mainstream education: refusal of enrolment, suspension, and expulsion.
- ☐ Autism-specific schools have long waitlists and high fees, creating financial stress.
- ☐ Families experience burnout, financial hardship, and housing strain due to lack of adequate support.

Recommendations

- ☐ Provide dedicated, adequate funding directly to families – not just referrals to overstretched community services.
- ☐ Broaden allowable supports to include psychology, OT, speech, behavioural therapy, psychiatry, sensory tools, in-home supports, and respite.
- ☐ Ensure real choice and control for families in how funds are used to meet children's changing needs.
- ☐ Implement regular, responsive updates to funding that reflect developmental changes, especially for ages 0–8.
- ☐ Invest in regional health and therapy services, including paediatricians, psychiatrists, allied health, and autism specialists.
- ☐ Expand and properly fund autism-specific education options, and upskill teachers in mainstream schools.
- ☐ Enforce accountability for schools and programs that exclude autistic children from education and community activities.
- ☐ Provide support for families, including respite, financial assistance, and recognition of parental burnout.

Full Submission

Introduction

I am parent of multiple autistic children living in regional NSW. I welcome the Thriving Kids inquiry as an opportunity to share my lived experience of what has worked under current systems and what urgently needs to change.

What is Working

One of the strengths of the NDIS and related programs has been the funding provided to families to help cover therapy supports that would otherwise be unaffordable. Without this assistance, my children would have had little to no access to essential therapies such as speech, occupational therapy, psychology, or behavioural supports. This funding has allowed us to access at least some of the interventions needed to help our children develop and participate.

What Isn't Working / Challenges Faced

Despite this, many challenges remain. Families like mine face multiple barriers that prevent autistic children from thriving in school, in the community, and at home.

1. Funding cuts and restrictions

- ☐ As my children have grown, their therapy needs have increased significantly. Yet our funding has reduced year after year, with stricter rules on how it can be used.
- ☐ Families are told we cannot use funds for supports we actually need, including in-home supports, social and community participation, or sensory tools — even though these are evidence-based and effective.
- ☐ Excluding these supports under the label of 'parental responsibility' is unfair and discriminatory, leaving families burnt out and desperate.

2. Regional access barriers

- ☐ In regional NSW, there are very few professionals available. Many rural towns have only one or no paediatricians. Psychiatry services are even scarcer.
- ☐ Waitlists for autism assessments are often 1–3 years long. Even when funding is approved, families cannot find providers to deliver the supports.
- ☐ Telehealth is sometimes available but does not fully replace local, consistent access, and is often incompatible for supporting young children.

3. Lack of timely reviews and appropriate goals

- ☐ Children from 0–8 years change rapidly, with needs and goals shifting significantly each year.
- ☐ Despite this, plans are not updated regularly. My children are still on outdated toddler goals, even though they are older and need very different supports.

4. Education exclusion

- ☐ Autistic children face record levels of suspension, expulsion, and refusal of enrolment in schools.
- ☐ My own children were refused entry into mainstream schools due to their diagnosis and excluded from every before- and after-school or school holiday program in our area.
- ☐ Nationally, more than one-third of families report their child with autism was discouraged or refused enrolment in school. In NSW, children with disability represent a disproportionately high number of suspensions and expulsions.
- ☐ Autism-specific schools exist but are few, expensive, and have years-long waitlists. Fees are often double those of other private schools, creating enormous financial strain.

5. Family stress and financial strain

- ☐ Families are forced to pay out-of-pocket for therapies, assessments, and sensory items not covered by NDIS.
- ☐ Parents often forced to reduce or leave work to care for their children, leading to loss of income, financial hardship, and housing stress.
- ☐ Cost of living pressures make this even more unsustainable.

Recommendations

To make the Thriving Kids Program truly supportive, it must include:

- ☐ Provide dedicated, adequate funding directly to families – not just referrals to overstretched community services.
- ☐ Broaden allowable supports to include psychology, OT, speech, behavioural therapy, psychiatry, sensory tools, in-home supports, and respite.
- ☐ Ensure real choice and control for families in how funds are used to meet children's changing needs.
- ☐ Implement regular, responsive updates to funding that reflect developmental changes, especially for ages 0–8.
- ☐ Invest in regional health and therapy services, including paediatricians, psychiatrists, allied health, and autism specialists.
- ☐ Expand and properly fund autism-specific education options and upskill teachers in mainstream schools.
- ☐ Enforce accountability for schools and programs that exclude autistic children from education and community activities.
- ☐ Provide support for families, including respite, financial assistance, and recognition of parental burnout.

Closing

Right now, being born autistic in Australia means facing exclusion not only from school and community life, but increasingly from the very systems designed to support families. The Thriving Kids Program is a chance to change that.

Families like mine need consistent, flexible funding; accessible local services; inclusive education; and recognition of the pressures parents face. With these changes, autistic children and their families will finally have a fair chance to thrive.