Mental Health Carers NSW Inc.

Submission to the Parliamentary Inquiry into the *Thriving Kids* Initiative

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About Mental Health Carers NSW (MHCN)

Mental Health Carers NSW (MHCN) is the peak body for carers of people who experience mental health challenges in NSW. MHCN is a community managed organisation that provides systemic advocacy, capacity development and education for carers, family, friends, and kin of those experiencing mental health challenges across NSW.

In Australia, there are approximately 354,000 mental health carers who, each year, provide 186 million hours of unpaid support.1 Due to the demands of their caring role, carers are at a high risk of developing mental health issues, as well as experiencing loneliness and social isolation. MHCN supports mental health carers and advocates for services and systems that support them in their caring role. MHCN ensures the voices of mental health carers in NSW, and the people they care for, are represented in policy and service reform processes. We work to uphold the rights of carers and consumers to equitable, accessible, and adequately funded mental health services.

MHCN empowers mental health carers to become champions for mental health reform and advocacy. We engage regularly with carers so they can inform us of our policy priorities and advocacy; for example, every month we convene the Carers of Forensic and Corrections Patients Network meetings, and peer led Mental Health Carer Connection meetings.

MHCN also provides the Disability Advocacy Futures Program. This program engages in systemic advocacy on behalf of those who experience psychosocial disability. In this role MHCN advocates to non-Health state government services regarding barriers to access and inclusion.

MHCN is funded by the NSW Ministry of Health and the NSW Department of Communities and Justice. We are a foundation member of Mental Health Carers Australia.

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[1] Diminic, S., Lee, Y. Y., Hielscher, E., Harris, M. G., Kealton, J., & Whiteford, H. A. (2021). 'Quantifying the size of the informal care sector for Australian adults with mental illness: Caring hours and replacement cost', *Social Psychiatry and Psychiatric Epidemiology*, 56(3), 387–400.

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Executive Summary

The *Thriving Kids* program has potential to strengthen early developmental supports, but its current framing raises serious risks for children with autism and developmental delay, their families, and carers. Any premature withdrawal of NDIS supports could create harmful service gaps, particularly in rural and remote areas, while reliance on overstretched mainstream systems risks further inequity. The use of outdated diagnostic labels such as "mild to moderate autism" undermines a neuro-affirming approach and creates uncertainty for families.

To ensure reform delivers positive generational change, Mental Health Carers NSW recommends:

1. No cuts to existing NDIS packages until *Thriving Kids* is fully co-designed, funded, and operational.
2. Genuine consultation with autistic people, families, and carers, embedding lived experience and cultural diversity.
3. Clarity of purpose, eligibility, and safeguards to ensure equitable and inclusive access.

Done well, *Thriving Kids* could create a more coordinated and affirming system of support, but only if reform is guided by the principle of "*nothing about us, without us*."

Scope of this Submission

This submission addresses the following terms of references as published by Inquiry into *Thriving Kids* regarding:

- 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.
- 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, care, and schools.
- Identify equity and intersectional issues, in particular, children who identify as First Nations and culturally and linguistically diverse.
- Identify gaps in workforce support and training required to deliver Thriving Kids.

- Draw on domestic and international policy experience and best practice.
- Identify mechanisms that would allow a seamless transition through mainstream systems for all children with mild to moderate support needs.

Introduction

The announcement of the *Thriving Kids* program represents a significant shift in how early developmental support will be structured for children with autism and developmental delay. While the intent of reform is commendable, the current framing of the program raises serious concerns for children, families, and carers who depend on the National Disability Insurance Scheme (NDIS) to access life-changing supports.

In a global context where autism is being singled out as something ‘caused by Tylenol (Panadol)’, MHCN holds grave concerns for the further stigmatisation of autism and the resultant mental health outcomes for children, families, and carers. The government’s emphasis on NDIS costs risks positioning children with developmental differences and neurodivergence as a budgetary burden rather than affirming their right to equitable and accessible support.

Mental Health Carers NSW opted to contribute this submission in recognition that neurodivergence can also come with mental health issues particularly when diagnosis is inaccessible and support is unaffordable.[2] We also highlight the importance of family and carers to the development of children with autism.

The proposed transition to *Thriving Kids* must be carefully and transparently managed to avoid uncertainty and service gaps. Autism has always been included in the NDIS, and any eligibility changes must not stigmatise or diminish the value of any child.

A premature withdrawal of NDIS support would leave families and carers struggling to meet needs within already overstretched education, health, and community systems. Without clarity of purpose, transparent communication, and genuine co-design with autistic people, families, and carers, the program risks undermining trust and effectiveness.

This submission includes valuable lived experience and service navigation expertise from a parent of an autistic child and support assistant for autistic children and sets out three core recommendations:

1. No cuts to existing NDIS packages while *Thriving Kids* is developed and implemented, to safeguard children from harm and ensure stability during reform.

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[2] Meng-Chaun, L., (2023). ‘Mental health challenges faced by autistic people’, *Nature Human Behaviour* 7, 1620-1637.

2. Genuine consultation with autistic people, families, and carers, recognising lived experience as essential to effective service design.
3. Clarity of purpose, eligibility, and safeguards, to ensure *Thriving Kids* delivers equitable, neuro-affirming, and inclusive support.

At its best, *Thriving Kids* could create generational change. For this to happen, reform must be guided by the principle of “nothing about us, without us”. It must be grounded in co design, clear communication, and respect for the rights and dignities of children, families, and carers.

Recommendations

Recommendation 1: No cuts to existing NDIS packages while *Thriving Kids* is in development and implementation

In the announcement of *Thriving Kids,* Minister Butler addressed concerns about NDIS costs, attributing part of the growth to increased diagnoses of autistic children and development delay. There is not a case of overdiagnosis; rather, it reflects better community awareness and support-seeking by families. Framing this as a budgetary burden directs unfair scrutiny towards disabled children instead of addressing systemic issues such as provider misspending and fraud.

In 2022-2023, NDIS spending for autistic children was approximately $3.1 billion, compared with the $2 billion allocated to *Thriving Kids.* The government should clearly explain how this reduced funding will adequately meet children’s needs, and whether it will be indexed to keep pace with demand and growth.

Mitigate uncertainty through safeguards and ongoing communication

The Department of Social Services and the NDIS must have ongoing transparency with stakeholders throughout the development and implementation of *Thriving Kids.* This will help minimize shockwaves felt and support parents, families and carers to provide support to the children this program is targeted towards.

Thriving Kids, if done in genuine co-design and with the principle of *“nothing about us, without us”* at its core, has immense potential for generational change. To ensure public trust and service uptake, there must be no cuts to NDIS packages until a fully co-designed and equitably funded program exists.

Coordinate across departments for a seamless transition and reduce gaps in service delivery

The 12-month goal towards implementation is ambitious and risks creating significant stress and harm for children, families, and carers. Cuts to NDIS services intended to be replaced by *Thriving Kids* must be delayed until the new program is fully established and proven effective. Careful sequencing of implementation, in collaboration with the NDIA, is essential to prevent children being left without support.

The proposal to remove children developmental delays and "mild to moderate autism" from NDIS Early Intervention funding is particularly concerning. With program parameters still undefined, there is a serious risk of placing children into an unclear and untested system, especially in rural and remote areas where services, playgroups, schools, clinics, and community services are already scarce.

If *Thriving Kids* relies on 'broad-based mainstream services' such as education and health, those systems will require substantial redesign as they currently struggle to meet the needs of all children.[3] here must be mechanisms for seamless transition through mainstream systems including:

- Early identification and referral pathways, including clear referral processes from child health nurses, GPs, and early educators into appropriate services (e.g., speech therapy, early intervention).
- Integrated case management, including coordinated planning between health, education, and social services to avoid duplication and gaps.
- A key worker approach that offers a single point of contact (caseworker or key worker) to guide families through different systems.
- Collaborative information sharing, including secure communication platforms so professionals (schools, therapists, health providers) can share progress and plans.
- Flexible support within mainstream settings, such as adjustments in childcare, schools, and community programs (e.g., small group learning, classroom aids, modified activities).
- Transition planning meetings, such as structured planning sessions when a child moves between services (e.g., childcare to school, primary to secondary).
- Culturally safe and inclusive practices such as tailoring support to reflect diverse cultural, linguistic, and community needs.

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[3] Evidence from the Disability Royal Commission, Productivity Commission, and AEDC 2024 have all found systemic under resourcing and inequity leading to long waitlists for developmental assessments and early intervention.

Recommendation 2: *Thriving Kids* must be developed in genuine co-design with autistic people, families, and carers

Involvement of lived experience and practical knowledge

The Government must demonstrate consultation with families and carers of autistic people because it is essential for effective and responsive service design.[4] Lived experience offers deep insight into the realities that policies and services aim to address.[5] Reflecting cultural and linguistic diversity in consultations recognises and includes the intersectional aspects of lived experience.[6] This will help identify equity and intersectional issues and determine robust solutions through co-design.

Families and carers understand the daily challenges of accessing services; they know the gaps between what services are supposed to provide and what really happens.[7] By involving them, the government will gain practical knowledge around how to provide services that are neuro-affirming, relevant, inclusive, and accessible across states.

The existing workforce needs more support. There is limited training available in early identification and training in digital literacy including online platforms, telehealth, and data systems. Inconsistent knowledge of child development across health, education, and social services and a lack of cross-sector collaboration in training results in fragmented service delivery.[8] This also impacts culturally safe and inclusive practices, particularly for Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse communities, as well as trauma-informed practices and mental health literacy.[9]

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[4] Bailey, S., Boddy, K., Briscoe, S., & Morris, C., (2014). 'Involving disabled children and young people as partners in research: a systematic review', *Child: Care, Health, and Development* 41(4), 505-514; Chown, N., et. al., 'Improving research about us, with us: a draft framework for inclusive autism research', *Disability & Society* 32, 1-15.

[5] Raymaker, D., & Nicolaidis, C., (2014). 'Participatory research with autistic communities: shifting the system', in J. Davidson & M. Orsini (eds.), *Worlds of Autism: Across the Spectrum of Neurological Difference* (Minnesota: Minnesota University Press), 169-188.

[6] Nicolaidis, C., & Raymaker, D., (2015). 'Community based participatory research with communities defined by race, ethnicity, and disability: translating theory to practice', in H. Bradbury (ed.) *The SAGE Handbook of Action Research.* (California: SAGE Publications), 167-179.

[7] Fletcher-Watson, S., et. al., (2019). 'Making the future together: Shaping autism research through meaningful participation', *Autism* 23(4), 943-953.

[8] Tinner, L., et al., (2023). 'Use of intersectionality theory in interventional health research in high-income countries: a scoping review', *International Journal of Environmental Research and Public Health* 20(14), 6370.

[9] O'Brien, J., Fossey, E., & Palmer, V. J., (2021). 'A scoping review of the use of co-design methods with culturally and linguistically diverse communities to improve or adapt mental health services', *Health and Social Care in the Community* 29(1), 1-17; Butler, T., et. al., (2022). 'A comprehensive review of

With a limited workforce capacity, particularly for speech pathologists, occupational therapists, and psychologists, there is a strong need for professional development in family engagement strategies to empower families and carers as partners in service delivery.

Honouring the role of families and carers for best practice

Support must also be family focused.[10] Families and carers know the gaps in existing services. The National Autism Strategy 2025-2031 recognised that families continue to encounter inconsistent support because of inconsistent approaches to diagnoses and dependence on individual NDIS providers.[11] Consulting them to fix service and coordination gaps leads to services that are easier to navigate and access.[12] Supports designed with families and carers are more person-centred and responsive, acknowledging the diversity of autistic people.[13]

For example, Aotearoa New Zealand's *Autism Guideline (3rd ed.)* converted lived experience into concrete recommendations that clinicians, services, and schools can implement while also being culturally inclusive.[14] The *Thriving Kids* program must follow the changes outlined by autistic people, families, and carers in the *First Action Plan* in the *National Autism Strategy 2025-2031*, including ensuring that the Oversight Council includes a diverse range of community members who ensure concrete service design outcomes.

Families and carers fill service and workforce gaps

Parent and carer wellbeing directly impacts child wellbeing.[15] The *Thriving Kids* program development and implementation must support parents and caregivers because they

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optimal approaches to co-design in health with First Nations Australians', *International Journal of Environmental Research and Public Health* 19(23), 16166; Poon, A. W. B., Karan, P., et. al., (2025). 'A scoping review of access and engagement with mental health services by young people from culturally and linguistically diverse communities in Australia', *Australian Journal of Social Issues* 0, 1-12.

[10] McIntyre, L. L., & Kunze, M., (2021). 'Family-focused interventions as prevention and early intervention of behavioural problems in children with autism spectrum disorder', *International Review of Research in Developmental Disabilities* 61, 159-191.

[11] Autism Australia, (2023). *National Parent & Carer Survey Report,* National Disability Insurance Scheme, *Autism Summary June 2023.*

[12] Bib, J., et. al., (2024). 'The co-design of a children's health and wellbeing local model of care to embed early mental health intervention and prevention within community ecosystems', *Mental Health & Prevention* 40, 200457.

[13] Parliament of Australia, (2022). *Services, Support and Life Outcomes for Autistic Australians*, 7.35.

[14] Taylor, L.J., et. al., (2021). 'An investigation of adherence to best practice guidelines for autism diagnosis in New Zealand', *Autism* 25(7), 2087-2100.

[15] Risi, A., J. A., Pickard, & A. L. Bird, (2021). 'The implications of parent mental health and wellbeing for parent-child attachment: a systematic review', *PLOS One* 16(12), e026891.

bridge service gaps.[16] The program announcement acknowledged allied workforce shortages, which are at crisis levels, particularly across NSW.

Families and carers need education, capacity building, peer support, mental health support, and respite to recognise developmental differences early and build wellbeing.[17] Instead of providing referrals to overextended community services, families and carers need affordable and equitable access to best practice resources, early developmental monitoring and screening, and affordable assessment.

There are several family-friendly ways to ensure children move smoothly between services, such as:

- Early checks and quick referrals if concerns are noticed
- One key worker or contact person to guide families.
- Professionals share information so parents don't have to repeat their story each time.
- Additional help in schools and childcare (e.g., learning support or smaller groups).
- Planning meetings prior to big changes (e.g., starting school)
- Clear guides and advice for families and carers about what services are available.
- Respect for different cultural and family needs in the support process.

Recommendation 3: *Thriving Kids* must have clarity of purpose and eligibility for ease of service navigation and support access

Thriving Kids has potential to strengthen family supports, however, the announcement as it stands has created uncertainty and hurt. The program must communicate its purpose, eligibility, and safeguards clearly, because autism has always been included in the NDIS and its removal risks stigmatisation and ableism. At present, *Thriving Kids* appears to be a tiered system based on unclear definitions of mild to "moderate" which families may find outdated or offensive.

Without clarity of purpose, autistic people, families and carers may feel that autism is being singled out to reduce NDIS spending. There must be navigational clarity that explains what services or departments cover what so that families and carers know exactly what to do, who to contact, and how the program works.

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[16] Fast, J., et. al., (2024). 'Valuing the contributions of family caregivers to the care economy', *Journal of Family and Economic Issues* 45, 236-249.

[17] Lancaster, K., et. al., (2023). 'Effectiveness of peer support programmes for improving wellbeing and quality of life in parents/carers of children with disability or chronic illness: a systematic review', *Child: Care, Health and Development* 49(3), 485-496.

Flexibility to accommodate diverse support needs

There must be a clear explanation of eligibility criteria and clear guidelines. There are concerns for how the program might impact service and NDIS accessibility for autistic people who are not children. Moreover, recognising that autism is a lifelong condition, it must be clear when/how people age out of *Thriving Kids* and what will be in place to support them to address whole of life needs.[18]

Resources and consideration must be given to regional and rural areas to prevent people in those areas experiencing more service black holes than they already do.[19] *Thriving Kids* will inevitably cater more to urban dwellers owing to higher density providers and services thus it is essential that the program have express accommodations for hard-to-reach populations.

Appropriate language and the social model

The diagnostic language used in the announcement of *Thriving Kids* could be interpreted as a reinforcement of the medical model.[20] Diagnostic thresholds of 'mild to moderate' can be misleading, are not neuro-affirming, and does not reflect best practice.[21] Severity labels flatten complex needs into categories that may overlook children's unique needs.

From this, there is a risk that children will slip through the cracks because they are "not disabled enough" thereby preventing early intervention and risking poor mental health and social outcomes as these children grow up. Moreover, the reliance on Medicare and GP-based supports reinforces the medical model when solutions require a social model based on the understanding that environs and attitudes shape disability experiences and commit to human rights and disability justice.[22]

Conclusion

We want *Thriving Kids* to work. It offers an opportunity to reshape early childhood supports however, if implemented early and without proper safeguards, clarity, or co-design, it risks

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[18] Parliament of Australia, (2022). *Services, Support and Life Outcomes for Autistic Australians*, 5.62, 5.34, 5.38, 5.60, 5.62,

[19] Gosse, G., et. al., (2025). 'Child development allied health services in rural and remote areas: a systematic scoping review of drivers, barriers and enabling strategies to delivery of services', *Australian Journal of Rural Health* 33(1), e70010.

[20] Parliament of Australia, (2022). *Services, Support and Life Outcomes for Autistic Australians*, 1.4 (p.361).

[21] Bottini, S., et. al., (2024). 'Moving from disorder to difference: a systematic review of recent language use in autism research', *Autism in Adulthood* 6 (2), https://doi.org/10.1089/aut.2023.0030

[22] Iyall Smith, K. E., (2021). 'Understanding and promoting the human rights of autistic people', *Societies Without Borders* 15.1.

creating new uncertainties and widening service gaps at a time in a child's life when stability and safety are key.

To deliver on its promise, reform must not come at the cost of those already supported through the NDIS. No cuts should occur until *Thriving Kids* is fully developed, properly funded, and proven to meet demand. Embedding the voices of autistic people, families, and carers is essential to ensuring services are practical and accessible. Likewise, clear eligibility criteria, transparent communication, and better coordination across government systems are critical to avoid harm and build public trust.

If guided by the principle of "nothing about us, without us", *Thriving Kids* can move beyond cost-containment narratives and measures to create meaningful change. By protecting existing supports while building a co-designed and inclusive system, the government can demonstrate its commitment to children's rights, family wellbeing, and a future where all children can thrive.