Submission by Carers WA on behalf of the National Carer Network:

Inquiry into the Thriving Kids initiative

3 October 2025

Contents

1.0 Recommendations

1. The Thriving Kids initiative uphold and embed the principles for recognising, including and supporting Australian carers as outlined in the *Carers Recognition Act 2010* (Cth) and the Statement for Australia's Carers.
2. The Thriving Kids initiative align with the National Carers Strategy and National Carers Strategy Action Plan.
3. The Thriving Kids initiative uphold and embed the rights of people with disability and of children as outlined in the UN CRPD and UN CRC.
4. The Thriving Kids Initiative align with key early childhood legislation, policies and strategies such as the National Action Plan for the Health of Children and Young People 2020-2030.
5. Government partner with the National Carer Network, carers, families and children to delineate and consult on plans for consultation, Thriving Kids program development, implementation and evaluation.
6. Government partner with the National Carer Network on the development and implementation of the Thriving Kids initiative.
7. The timeframe for development and implementation of the Thriving Kids initiative be extended.
8. Consultation timeframes for the Thriving Kids initiative be extended and expanded to include additional consultation methods to increase accessibility for people and children with disability, their families and carers.
9. A consultation plan be released outlining the development timeframe and planned consultations over this timeframe, to allow increased time for stakeholders to prepare feedback and information to better inform program development.
10. Carer access to respite be addressed as part of the Inquiry into the Thriving Kids Initiative.
11. Carer wellbeing and respite be prioritised with a particular focus on support for young carers and siblings (carers aged 0-25 years), in line with the UNCRC and other UN Conventions as relevant. Young carers are also recommended to be considered in every sector and service setting in which the Thriving Kids initiative will operate, with national consistency.
12. The Thriving Kids initiative embrace flexible, accessible, and functional needs-based pathways to diagnosis and support, and for reforms to be grounded in best practice and evidence.
13. Development of clear, accessible information and resources to empower parents and carers to identify developmental concerns early and seek appropriate support.

14. The development of a targeted awareness and communication campaign, aligned to the National Autism Strategy, which also supports understanding and identification of developmental delay. This campaign would also include targeted engagement with health professionals to support them in increased carer identification and referral, aligning with the actions in the National Carer Strategy.
15. The development of accessible and free brochures, apps, short and long form videos, and online developmental checkers which are designed in collaboration with parents and carers, in a way that is supportive, evidence-based, neuro-affirming, culturally safe and translatable as required.
16. Increased clarity be provided on Thriving Kids eligibility, including a definition of the meaning of 'mild to moderate' autism and developmental delay; and transparency throughout program development and implementation.
17. Clarity be provided as to whether the new program will streamline, duplicate or replace current supports, and on the roles and relationships between programs.
18. Transparent and independent evaluations be conducted of initiatives designed to support autistic children and those with developmental delay, before they are incorporated into a program such as Thriving Kids.
19. Clear communication and safeguards, and transparency about how new initiatives will interact with the NDIS.
20. The suspension of any rule making around reassessment of children under 9 with autism or developmental delay until Thriving Kids is operational.
21. Assessments and reassessments for autistic children and adults, and those with permanent developmental delay, remain consistent with the *NDIS Act 2013* (Cth) (with the application of Recommendation 20 of this submission).
22. National consistency within Thriving Kids reforms to ensure all children, families and carers, regardless of location, have equitable access to high-quality supports.
23. Investment in workforce development, training and support to ensure providers are equipped to meet the needs of children, carers and families in regional areas.
24. Targeted strategies, including culturally appropriate services and outreach, to address inequities faced by children, families and carers from culturally, linguistically, and socioeconomically diverse backgrounds.
25. Targeted strategies and authentic codesign of services for children, families and carers from First Nations and CALD backgrounds.
26. Investment in workforce development, training, and support to ensure providers are equipped to meet the needs of children, families and carers in the Thriving Kids initiative.
27. The Inquiry considers workforce supports for carers, as well as initiatives which enable carers to return to the workforce, as a key prospective workforce resource for the Thriving Kids initiative. This should also include funded peer workers and support roles.
28. The NCN recommends medical and health professionals in all healthcare settings should be given training to support parents and carers and help identify developmental delay and/or autism, noting gender and cultural differences.

29. Introduce minimum standards in safety and training as part of the onboarding process for early childhood workers.
30. Childcare spaces in regional and remote areas be increased.
31. The availability of childcare, vacation care and outside school hours care for children with additional needs be significantly increased.
32. Initiatives are implemented to expand access to therapists, allied health professionals and early childhood specialists, including in regional and remote areas.
33. The Inquiry include a significant package of support and education for schools if they are to be involved in the Thriving Kids initiative. Fair, adequate, and sustainable funding models across all Australian schools must take a strong focus alongside the Thriving Kids Initiative.
34. The Thriving Kids initiative align with human rights standards such as the UNCRPD and UNCRC, as well as carers rights standards as outlined in the *Carer Recognition Act 2010* (Cth) and Statement for Australia's Carers.
35. The Thriving Kids initiative align with and embed practices as seen in key strategies such as the National Autism Strategy, the Early Years Strategy, the National Carer Strategy and Action Plan, Australia's Disability Strategy and National Action Plan for the Health of Children and Young People 2020-2030.
36. Where relevant, the Thriving Kids initiative should also align with relevant carer recognition legislation, as well as other relevant legislation, policies and standards within each state and territory.
37. Development of a robust and thorough evaluation framework to assess the effectiveness of the Thriving Kids Initiative, delivering continuity of care, neuro-affirming support, and facilitate positive outcomes for children, their families and carers.
38. Transition and service access support for carers and families be considered as part of the Thriving Kids program.
39. Any staff member who is transitioning families between services to undergo trauma informed training, as well as training in carer, disability, neurodiversity and cultural competency awareness training.
40. Appropriate resourcing for all services involved in the Thriving Kids initiative.
41. Transition and referral pathways between all services and touch points.
42. Expansion of the Disability Standards for Education to include outside school hours care, with national consistency in funding and programs to increase equity.

2.0 Introduction

The National Carer Network (NCN) appreciates the opportunity to provide feedback to the Standing Committee on Health, Aged Care and Disability in response to its Inquiry into the Thriving Kids initiative. This submission is provided on behalf of the National Carer Network, consisting of Carers Australia, Carers WA, Carers NSW, Carers Tasmania, Carers ACT, Carers Victoria, Carers NT, Carers QLD and Carers SA.

The NCN is supportive of government action on the development of foundational supports outside of the NDIS and looks forward to being part of the development of the Thriving Kids initiative as part of this suite of supports. To this end, a range of recommended measures for the successful development and implementation of the Thriving Kids initiative have been detailed within this submission.

For the purposes of this submission, the term 'carer' is defined as per the meaning under the *Carer Recognition Act 2010* (Cth), this being that a carer is an individual who provides personal care, support and assistance to another individual who has disability, a medical condition (including a terminal or chronic illness), a mental illness, or who is frail and aged. An individual is not a carer if the care, support or assistance provided is under a contract or services or for provision of services, is in the course of voluntary work for a charitable, welfare or community organisation, or is provided as part of an education or training course.[1]

This submission has been informed by ongoing feedback from carers and stakeholders across Australia.

[1] (Commonwealth of Australia, 2010)

3.0 General Feedback

3.1 Context

'Families shouldn't have to fight this hard just to get basic, disability-related needs met.' – response from a carer

3.1.1 Australian Carers

There are over three million unpaid carers in Australia[2], who provide informal care that is valued at $77.9 billion per annum[3]. This care is provided at significant long-term cost to the carer's financial and general wellbeing, with little recognition or support. It is from this context which carers live every day, advocate for the person they care for, and respond to changes in programs and services that they navigate and use on behalf of those they care for – such as those which are being considered within the Inquiry into the Thriving Kids Initiative.

In the context of this submission, it is also important to note that many carers themselves have disability. The most recent data indicates that 39% of carers in Australia have a disability, up from 32% in 2018.[4]

Financial impact

In the course of providing care, Australian carers forgo (on average per carer) $392,500 in lifetime savings and $170,000 in superannuation to age 67. For long term carers, such as those who are caring for a child or sibling into adulthood and further, this financial impact of caring is elevated to a loss of at least $940,000 in lifetime income and $444,500 in retirement savings[5]. The 2024 National Carer Survey highlighted that, most commonly, a carer will be someone caring for their child (including adult children) (44.4%)[6].

Further to the long-term financial cost of caring, far too many Australian carers also have trouble accessing basic necessities. Some carers report never having enough food (4.3%), with a further 6.9% only sometimes having enough food. Another 6.1% of carers report either never or only sometimes having a safe place to live[7]. Nearly one in four carers said they only sometimes (19.7%) or never (4.3%) had access to affordable healthcare[8] – this is in addition to carers not prioritising their own health over that of the person they care for or having the time away from their caring role to attend to their own health.[9]

One in ten carers report not being able to pay rent or mortgage payments on time, 18.3% report not being able to pay household bills on time, or being able to cool or heat their home (11.8%).[10]

[2] (Australian Bureau of Statistics, 2024)
[3] (Deloitte Access Economics, 2020)
[4] (Australian Bureau of Statistics, 2022)
[5] (Furnival & Cullen, 2022)
[6] (Carers NSW, 2025)
[7] (Carers NSW, 2025)
[8] (Carers NSW, 2025)
[9] (Carers NSW, 2025)
[10] (Carers NSW, 2025)

In addition to these cost-of-living impacts, many carers struggle to work due to their caring role, or are not able to work full time and must prioritise workplace flexibility over more senior positions[11]. This is particularly pronounced in the early childhood space, especially if a child being cared for cannot attend childcare or vacation care. In the 2024 National Carer Survey, one in four carers were not in the labour force; half of respondents were of working age (15-64 years old); just above one in three carers were in paid employment; and 7.6% of respondents were unemployed.[12]

Of those involved in the survey, more than a third of carers (37.7%) and more than one in five of carers in the paid workforce, said they had stopped working on a temporary or permanent basis due to their caring responsibilities. Most respondents (58.6%) also reported at least one form of financial stress.[13]

Impact on wellbeing

Being in a caring role comes at a significant cost to a carer's wellbeing, and economic and financial security. Carers have significantly higher rates of psychological distress than the average Australian. Over half of carers have poor wellbeing, compared to 25.4% of adult Australians. Only 17.1% of carers reported having good health, compared to 47.9% for the average Australian[14]. Preventative measures are needed to prevent carer burnout and further pressure on the many systems and services that carers navigate, use and fill in service gaps for on behalf of those they care for.

Given the above, the prospect of being in a caring role is not a positive one. However, the reality is that everyone will either currently be in a caring role, be in a caring role in the future, or need care themselves. While the demand for carers is projected to increase by 23% by 2030, the number of carers is only projected to increase by 16% over this timeframe[15]. Without improvements to practical recognition and support for carers, this shortfall will only worsen over time.

Impact of formal recognition

Many Australian carers do not feel recognised or valued in their caring role. In Australia, 57.6% of carers provided care for someone accessing disability services, and one in five carers provide care for someone not accessing any formal support services.[16] Across all services, carers were commonly not asked about their needs as a carer, including in mental health services (66.7% of carers), disability services (65.8%) and aged care services (55.1%).[17]

Independent analysis of the WA results of the 2024 National Carer Survey indicated this lack of acknowledgement and recognition impacts on carers' level of wellbeing and on their ability to perform their caring role, have longevity in this role, and thrive outside of their caring role. Increasing levels of formal carer recognition can lift carer wellbeing and positively impact other related areas of their lives, including levels of recognition of their caring role from family, friends and those they care for – which in turn further boosts carer wellbeing[18].

[11] (Carers NSW, 2025)
[12] (Carers NSW, 2025)
[13] (Carers NSW, 2025)
[14] (Carers NSW, 2025)
[15] (Deloitte Access Economics, 2020)
[16] (Carers NSW, 2025)
[17] (Carers NSW, 2025)
[18] (SAGE Design and Advisory, 2025)

3.2 Human Rights

The National Carer Network (NCN) endorses and works to uphold the rights of Australian carers, people with disability and children.

3.2.1 Obligations to Australian Carers

The principles for recognising, including and supporting Australian carers are outlined within the Statement for Australia's Carers under the *Carer Recognition Act 2010* (Cth). This statement outlines how carers should be treated as individuals, and also in their caring role, which together incorporate essential elements which must be embedded within the Thriving Kids initiative and broader foundational supports offerings. Ensuring carers are embraced as true partners in care, who are also supported as individuals, carries significant positive impact and cost benefits for both government and community. The NCN is keen to partner with government to ensure the rights of Australian carers are embedded within Thriving Kids and other foundational supports initiatives.

Carers as individuals within the Statement for Australia's Carers:

- All carers should have the same rights, choices and opportunities as other Australians, regardless of age, race, sex, disability, sexuality, religious or political beliefs, Aboriginal or Torres Strait Islander heritage, cultural or linguistic differences, socioeconomic status or locality.
- Children and young people who are carers should have the same rights as all children and young people and should be supported to reach their full potential.
- Carers should be acknowledged as individuals with their own needs within and beyond the caring role.
- Carers should be supported to enjoy optimum health and social wellbeing and to participate in family, social and community life.
- Carers should be supported to achieve greater economic wellbeing and sustainability and, where appropriate, should have opportunities to participate in employment and education.
- The valuable social and economic contribution that carers make to society should be recognised and supported.[19]

Carers as part of their caring role within the Statement for Australia's Carers:

- The relationship between carers and the persons for whom they care should be recognised and respected.
- Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.
- Carers should be treated with dignity and respect.
- Support for carers should be timely, responsive, appropriate and accessible.[20]

These implementation of these rights for carers is assisted by the measures recommended in the National Carers Strategy[21] and the National Carers Strategy Action Plan.[22]

[19] (Commonwealth of Australia, 2010)
[20] (Commonwealth of Australia, 2010)
[21] (Australian Government, 2024)
[22] (Australian Government, 2024)

3.2.1 Rights of Australians with Disability (including autism and developmental delay)

The National Carer Network (NCN) endorses the United Nations Convention on the Rights of Persons with Disabilities (CRPD), of which Australia is a signatory, and strongly believe in the important role that families and carers can play in supporting the rights of people with disability, where they have been nominated to do so.

Further, the NCN also endorses the United Nations Convention on the Rights of the Child (CRC), of which Australia is also a signatory. For the purposes of this submission, we draw particular attention to the following articles of this Convention (summarised):

- Article 12 – Children have the right to say what they think should happen when adults are making decisions that affect them and to have their opinions taken into account.
- Article 23 – Children who have any kind of disability should receive special care and support so they can live a full and independent life.
- Article 27 – Children have the right to a standard of living that is good enough to meet their physical and mental needs. The government should help families that cannot afford to provide this.
- Article 36 – Children should be protected from any activities that could harm their development[23].

The NCN is keen to partner with government to assist in ensuring the Thriving Kids initiative reflects and upholds the rights of people and children with disability, carers and families - from inception through to implementation and evaluation.

The National Action Plan for the Health of Children and Young People 2020-2030 states there is a crucial 'window of opportunity' which arises in early childhood to prevent or reduce adverse outcomes, maximise the life chances of children to thrive, and affect long-term individual health outcomes[24]. The National Action Plan further outlines the positive return on investment that is achieved through childhood health programs and interventions in childhood[25].

'Cost benefit analyses demonstrate a positive return on investment for health programs and interventions in childhood, acting as a powerful equaliser for children and young people experiencing disadvantage. When we invest wisely in children and young people, the next generation will pay that back through a lifetime of productivity and responsible citizenship' – National Action Plan for the Health of Children and Young People 2020-2030

Protective factors and opportunities to achieve positive change which are outlined in the National Action Plan include:

- Strengthened prevention and early intervention in the child's first 2000 days.
- Parent/carer support and skills development
- Promotion and programs supporting positive social and emotional wellbeing and preventative mental health[26].

These are opportunities and protective factors which would also be of benefit to child development and family/carer support within the Thriving Kids initiative.

[23] (United Nations, 2025)
[24] (Australian Government Department of Health, 2019)
[25] (Australian Government Department of Health, 2019)
[26] (Australian Government Department of Health, 2019)

The NCN recommends:

1.0 The Thriving Kids initiative uphold and embed the principles for recognising, including and supporting Australian carers as outlined in the *Carers Recognition Act 2010* (Cth) and the Schedule for Australia's Carers.

2.0 The Thriving Kids initiative align with the National Carers Strategy and National Carers Strategy Action Plan.

3.0 The Thriving Kids initiative uphold and embed the rights of people with disability and of children as outlined in the UN CRPD and UN CRC.

4.0 The Thriving Kids Initiative align with key early childhood legislation, policies and strategies such as the National Action Plan for the Health of Children and Young People 2020-2030.

5.0 Government partner with the National Carer Network, carers, families and children to delineate and consult on plans for consultation, Thriving Kids program development, implementation and evaluation.

3.3 Program Development and Implementation Opportunities

'Announcing policy shifts without detail creates unnecessary stress, anxiety, and harm for carers.' – feedback from a carer

Disability reform and services have progressed significantly since the signing of the National Disability Agreement in 2008, launch of the 'Every Australian Counts' campaign in 2011 and passing of the NDIS Bill in 2013. The ensuing thirteen years have seen the NDIS be trialled, rolled out, reviewed and progressively reformed[27]. This has been life changing for many NDIS participants and, where applicable, their carers.

A significant message of the NDIS Review was the lack of foundational supports outside of the NDIS, including for children, families and carers.[28] The need for this is not disputed. Indeed, the NCN is keen to partner with government to achieve the best outcomes for the Thriving Kids initiative and for the children, families and carers who will use and navigate the program.

To help to achieve this, the NCN recommends initial consideration be given to the following measures to support program development and provide increased certainty for the children, families and carers who will be impacted by the program.

Longer timeframes for program development and implementation

The NCN is concerned that the current timeframe for program development and implementation may not be sufficient to build a program which achieves the outcomes needed during the crucial early childhood 'window of opportunity'.[29] This concern is grounded in feedback from carers and in professional experience of program development timeframes.

It is recommended that the timeframe for program development be extended to July 2027, leaving a period of just under two years to develop the Thriving Kids program before initial implementation. It is also critical that this work proceeds with consideration of broader reforms under the NDIS, so that supports for adults with autism and other disability are seen as part of a life course approach to system design and implementation, and consultation processes are developed which allow their perspectives to be fully shared and considered as well.

Consultation timeframes and plan

The NCN recommends that consideration be given to extended consultation timeframes for the Inquiry, as well as increased methods of consultation, especially for people with disability and carers, and people in regional and remote areas. Examples of increased methods of consultation may include options for face-to-face, online and hybrid consultation sessions as part of the Inquiry. These options would be recommended to include mechanisms to ensure all people with disability are able to participate. We would also suggest that separate family and carer consultation sessions are also considered.

If these consultations are already planned as part of the Inquiry and program development, the NCN would greatly appreciate the publication of a consultation plan for the development timeframe of the Thriving Kids initiative. This would assist relevant stakeholders prepare information and feedback to assist in supporting the development of the program.

[27] (NDIS, 2023)
[28] (Commonwealth of Australia, 2023)
[29] (Australian Government Department of Health, 2019)

Clear and effective monitoring, accountability and evaluation

We need to have safeguards in place, the idea that some people are rorting the system. People rort the system with welfare, you just don't cut the welfare system for groups of people just for the budget. You try and figure out ways to make the system operate." – feedback from a carer

"It's already having an impact. You're seeing, lots of carers saying this and that online. Amongst myself and my friends, our stress levels are up, because we're you know, sorry to get emotional. The NDIS has been like a lifesaver for so many people with disabilities and families, and the idea that a 2 billion dollars is going to replace 42 billion dollars of support. It's quite scary." – feedback from a carer

"For me it's just the anxiety, realising the drop in funding down to $2 billion and then trying to get everyone to fit. There's questions about some of the things they are proposing and the evidence, like ABA… That's going to come at a cost to people." – feedback from a carer

Carers have raised concerns that the new Thriving Kids initiative will not adequately support the needs of their children, resulting in long-term impact and cost for their families, the community and government. Central to these concerns raised by carers is the reduction in available funding, what appears to be a lack of understanding of autism in announcements made concerning the program, and of the levels of support needed to support children with autism and developmental delay. Carers also raised concerns regarding some of the programs and methodologies proposed to be included in the Thriving Kids initiative.

The NCN recommends that the Thriving Kids initiative only include methods of support which are evidence-based with strong positive outcomes for children with autism and development delay, their families and carers. It is also recommended that strong monitoring and evaluation mechanisms are built in to track outcomes of the program for children, their families and carers. The NCN also calls for meaningful and comprehensive engagement with peak bodies, people and children with disability, their families and carers at every stage of service design and implementation.

Increased engagement with stakeholders on autism

"I am saddened and deeply concerned as Minister for Disability and the NDIA, about your lack of understanding of disability, its impacts on disabled people and their informal support systems. I am disgusted by your comments that show your ableism, suggesting that autism is 'mild' or is not a 'permanent' disability is uninformed. The Australian Government Institute of Health and Welfare website defines "Autism spectrum disorder (also simply termed autism) is a persistent developmental disorder." By the government's own definition autism is a permanent and lifelong disability." – feedback from a carer

Carers have raised that they are unhappy with the way that autism is being portrayed by government. The NCN recommends increased engagement with autistic people, their families and carers, and related peak bodies, on communications and other aspects of the Thriving Kids initiative. It is also suggested that education on autism be mandatory for people who will be involved in the development of this program.

The NCN recommends:

6.0 Government partner with the National Carer Network on the development and implementation of the Thriving Kids initiative.

7.0 The timeframe for development and implementation of the Thriving Kids initiative be extended.

8.0 Consultation timeframes for the Thriving Kids initiative be extended and expanded to include additional consultation methods to increase accessibility for people and children with disability, their families and carers.

9.0 A consultation plan be released outlining the development timeframe and planned consultations over this timeframe, to allow increased time for stakeholders to prepare feedback and information to better inform program development.

4.0 Feedback aligned to Inquiry Terms of Reference

4.1 Evidence based information and resources that could assist parents to identify if their child has mild to moderate development delay and support parents to provide support to these children.

4.1.1 Prioritisation of Carer Wellbeing and Respite

'These changes also directly affect carers. When children lose access to vital supports, the responsibility falls back onto carers who are already stretched beyond capacity. This not only increases stress and burnout, but also limits carers' ability to work, maintain their own health, and sustain family life. Cutting back supports for autistic children is, in effect, cutting back supports for the carers who hold everything together.' – feedback from a carer

Carers are central to the success of the Thriving Kids Initiative. They provide essential care, advocacy, and support, often at great personal cost to their health, wellbeing, financial security, and social participation. Government and service systems have a duty to recognise carers, reduce barriers, and ensure that any reforms improve rather than intensify the challenges they face.

Australian carers are already a cohort which have low financial and economic security, decreased physical and mental wellbeing, and who are often significantly isolated. They prioritise the people and children they care for above their own needs and can spend every waking moment caring for a loved one. It is from this place that the Inquiry asks of evidence-based information and resources to assist parents to identify development delay and support their children. The first issue is giving these families and carers the time and wellbeing to even read these resources.

Of the carers identified in the 2024 National Carer Survey that were providing care to a child aged 0-8, 19% were caring for a child with a developmental disability, and 81% were caring for a child with autism. While 80.5% of these carers were supporting someone with access to the NDIS, those who did not have access (19.5%) provided care for similar hours than those that did. Almost half cared for more than one person, which was mainly for multiple children.[30]

Data from four consecutive Carer Wellbeing Survey Reports (2021[31], 2022[32], 2023[33] and 2024[34]) showed that carers of autistic people and carers of people with developmental delay, were amongst the groups of carers with lower-than-average wellbeing.

[30] (Carers NSW, 2025)
[31] (University of Canberra (Regional Wellbeing Survey Team) & Carers Australia, 2021)
[32] (Schirmer, Mylek, & Miranti, 2022)
[33] (Myleck & Schirmer, 2023)
[34] (Mylek & Schirmer, 2024)

Overall, the health and wellbeing of carers of children aged 0-8 years was very low for both carers of children in receipt of NDIS and those without in comparison to other 2024 National Carer Survey results, indicative of a high need for the supports provided by the NDIS.[35] Further, this sub group of carers also had poorer access to the essentials than other carers. This included having enough food to not go hungry, a safe place to live, affordable health services, reliable internet and reliable transport.[36]

The NCN recommends that the issue of lack of respite for carers is addressed as part of this Inquiry, regardless of whether a child has a NDIS plan or not. In line with the *Carer Recognition Act 2010* (Cth), carers must be supported to enjoy optimum health and wellbeing; participate in family, social and community life; supported to achieve greater economic wellbeing and sustainability, including opportunities to participate in employment and education.[37] This is not possible without the provision of respite and the chance to take a break.

Further, under Article 24 of the Universal Declaration of Human Rights, *"everyone has the right to rest and leisure, including reasonable limitation of working hours and periodic holidays with pay,"* and Article 27 states *"everyone has the right freely to participate in the cultural life of the community."*[38]

In addition, where supports are provided to carers as part of foundational supports and the Thriving Kids initiative, the NCN strongly recommends these supports are practical (not just resilience-building), and that they are not impacted by undefined 'parental responsibility'.

Young Carers

There are more than 392,900 young carers in Australia[39]. Over 60% of these young carers are the primary carer to an adult in their life, and over 62% of young carers have heavy or very heavy caring responsibilities (20-50+ hours a week undertaking tasks related to caring). These tasks include things such as assistance with mobility, cooking, cleaning, looking after siblings, supporting with appointments and medicine administration, managing finances, and providing emotional support. Young carers are at greater risk of high psychological distress, are at higher risk of financial distress, are more susceptible to social isolation, financial & educational disadvantage, unemployment, and poor physical & mental health. Between 2022 and 2023, young carers aged 15-24 years saw a much higher than average decline in wellbeing. Indeed, 50% of young carers live in households that are close to or below the poverty line.[40] The long term impact is lower income earning capacity, lack of social engagement and poorer health and wellbeing outcomes for young people who are in a caring role.

It is recommended that carer wellbeing and respite be prioritised with a particular focus on support for young carers and siblings (carers aged 0-25 years), in line with the UNCRC and other UN Conventions as relevant. Young carers are also recommended to be considered in every sector and service setting in which the Thriving Kids initiative will operate, with national consistency.

[35] (Carers NSW, 2025)
[36] (Carers NSW, 2025)
[37] (Commonwealth of Australia, 2010)
[38] (United Nations General Assembly, 1948)
[39] **Invalid source specified.**
[40] (Carers WA, 2024)

For example, in educational settings support and recognition for young carers is significantly different depending on the jurisdiction:

- The Victorian Department of Education has a Young Carers – Identification and Support policy which states that when young carers are identified, it is to be recorded on their school administration system, support will be offered to the young person, and reasonable adjustments are made to support student learning[41].
- The Department of Education, Children and Young People in Tasmania define who a young carer is, outline the challenges a young carer may face and references the Carers Recognition Act 2023 (Tas) and the Tasmanian Carers Action Plan 2021-2024 and provides links to external resources for young carers and families as well as school staff[42].
- The ACT Education Directorate states a commitment to "recognising and supporting carers, and responding to the needs of carers, their rights, choices and opportunities to participate fully in all areas of life… A whole school approach to supporting the needs of young carers will impact positively on their ability to learn and their learning into the future. It is important all school staff are aware of the challenges which young carers face and the possible impact on their learning and wellbeing"[43].
- The Queensland Department of Education has a statement on young carers including definition of a young carer and resources for young carers and schools as well as promotional materials[44].
- The NSW Department of Education is currently working with their Inclusion and Wellbeing Directorate and Carers NSW to update their young carer information and make it more accessible on the website.
- In WA, its Department of Education website does not mention young carers and it does not have a formal policy for identification, recognition, or support of young carers.[45]

[41] (Victorian Department of Education, 2020)
[42] (Tasmanian Department for Education, Children and Young People, 2024)
[43] (ACT Education Directorate, 2024)
[44] (Queensland Department of Education, 2024)
[45] (Carers WA, 2024)

4.1.2 Diagnosis Pathways and Age Cutoffs

"Yes, the NDIS budget has increased and of course there are increasing numbers of children being diagnosed as autistic. However, to blame parents for seeking a diagnosis because they do it 'out of love' is absurd. As you rightly mentioned, parents are seeking a diagnosis, for the reason that their child is disabled, their child is autistic and has a permanent lifelong challenge. Parents are not engaging with multitudes of professionals, allied health services, teachers and completing endless paperwork for their enjoyment. Parents are doing so because they have a disabled child who needs support. More children are being diagnosed as autism is becoming more widely known about, stigma is reducing and parenting standards are changing. These are all good things." – feedback from a carer

Set age limits and complex diagnostic requirements in programs risk excluding children who are diagnosed later in life or who do not fit neatly into categories. The NCN believes that for Thriving Kids there is a need for flexible, accessible, and functional needs-based pathways to diagnosis and support, and for reforms to be grounded in best practice and evidence. There is also a need for clear, accessible information and resources to empower parents and carers to identify developmental concerns early and seek appropriate support.

Under the existing Early childhood approach, a diagnosis is not needed to start engagement with supports, and children are eligible for support where developmental concerns arise (without a diagnosis).[46] Taking a diagnosis first approach is also likely to see greater exclusion of children needing support who do not meet eligibility criteria. Instead, an approach that looks to support children with low to moderate support needs due to developmental concerns, is a much more inclusive approach.

<u>Resources</u>

Carers experience multiple challenges engaging with services and accessing and understanding relevant information, with carers of children with additional needs facing additional barriers to support. Carers report facing stigma and judgement from professionals, parents and other community members – which hinders identification and reaching out for support.

Actions such as awareness raising, identification and stigma reduction are ones central to other relevant strategies, reports and action plans such as Australia's Disability Strategy the Early Years Strategy, and the findings of the Assessment and Support Services for People with ADHD Report, following the Inquiry by the Senate Community Affairs References Committee.

The NCN recommends the development of a targeted awareness and communication campaign, aligned to the National Autism Strategy, which also supports understanding and identification of developmental delay. This campaign would also include targeted engagement with health professionals to support them in increased carer identification and referral, aligning with the actions in the National Carer Strategy.

[46] (NDIS, 2025)

In addition, the development of accessible and free brochures, apps, short and long form videos, and online developmental checkers could be useful guides to help parents and carers understand what they may expect at certain stages of their child's development. These are recommended to be designed in collaboration with parents and carers, in a way that is supportive, evidence-based, neuro-affirming, culturally safe and translatable as required.

Developmental discussions could also form part of parent and baby groups facilitated through Child and Family Learning Centres, Community Health Centres, Aboriginal-led services, and Playgroups. Evaluations of other effective models that support parents to identify developmental delay or concerns in infants and young children, would also be beneficial.

4.1.3 Clarity

'Another huge concern is the way these announcements have been made to the community without clear detail. This lack of transparency creates uncertainty and fear, leaving carers and families stressed and anxious about what supports may be taken away. For carers who are already stretched to their limits, the added emotional toll of not knowing what the future holds is incredibly damaging.' – feedback from a carer

Carers have raised that they are feeling anxious and uncertain about the Thriving Kids program, and that they are not sure about how the program will look, if their children will be impacted or not, and if their children will be able to access supports or have continuity of funding.

To help provide clarity to the families that may be impacted by this reform, the NCN recommends that more information is initially provided on the following details:

- Program eligibility, including a definition of the meaning of 'mild to moderate' autism and developmental delay.
- Clarity on which children will remain on the NDIS, and which will be moving to Thriving Kids.

The NCN also calls for transparency throughout the development and implementation of the Thriving Kids initiative.

The NCN recommends:

10.0 Carer access to respite be addressed as part of the Inquiry into the Thriving Kids Initiative.

11.0 Carer wellbeing and respite be prioritised with a particular focus on support for young carers and siblings (carers aged 0-25 years), in line with the UNCRC and other UN Conventions as relevant. Young carers are also recommended to be considered in every sector and service setting in which the Thriving Kids initiative will operate, with national consistency.

12.0 The Thriving Kids initiative embrace a flexible, accessible, and functional needs-based pathways to diagnosis and support, and for reforms to be grounded in best practice and evidence.

13.0 Development of clear, accessible information and resources to empower parents and carers to identify developmental concerns early and seek appropriate support.

14.0 The development of a targeted awareness and communication campaign, aligned to the National Autism Strategy, which also supports understanding and identification of developmental delay. This campaign would also include targeted engagement with health professionals to support them in increased carer identification and referral, aligning with the actions in the National Carer Strategy.

15.0 The development of accessible and free brochures, apps, short and long form videos, and online developmental checkers which are designed in collaboration with parents and carers, in a way that is supportive, evidence-based, neuro-affirming, culturally safe and translatable as required.

16.0 Increased clarity be provided on Thriving Kids eligibility, including a definition of the meaning of ‘mild to moderate’ autism and developmental delay; and transparency throughout program development and implementation.

4.2 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.

4.2.1 Clarity in Program Landscape

Carers have raised that they are uncertain about how the Thriving Kids program will fit with existing early childhood and disability programs. There is limited information and clarity as to whether the new program will streamline, duplicate or replace current supports, or the roles and relationships between programs. Ideally, the NCN would like to see the Thriving Kids initiative be a program which is focused on early identification, support and information provision – with referral pathways for those with autism and permanent development delay into the NDIS.

The NCN is pleased that the Inquiry is reviewing the effectiveness of relevant current and past programs and initiatives. However, the NCN would also like to raise the need for transparent and independent evaluation of initiatives designed to support autistic children and those with developmental delay, before they are incorporated into a program such as Thriving Kids. Programs. Additionally, it is important to review previous extensive reforms of supports for children with disability since the role out of the NDIS, such as the review of the Early Childhood Early Intervention approach or 'ECEI Reset'.[47]

The establishment of the Early childhood approach and Early connections programs by the NDIA following the ECEI reset have aimed to improve access to information and support for children living with disability, including developmental delay, their families and carers. However, evaluation of the effectiveness of these programs in meeting the proposed aims of the Thriving Kids initiative and opportunities to continue to build on this established approach should be evaluated before developing a new iteration of this program.

Further initiatives and policies raised by members of the NCN for such an independent and transparent evaluation include:

- Autism CRC – provides free resources to support professional and community capacity in Autism diagnosis, assessment and service provision.
- National Guideline for the Assessment and Diagnosis of Autism in Australia – outlines guiding principles, good practice points, and consensus-based recommendations with neuro-affirming approach.
- Positive Partnerships
- Autism Inclusion Teachers in South Australia – as well as an increased focus on embedded autism inclusion and support in early learning centres, kindergarten, play groups, schools and outside school hours care.
- Victorian Government program for intensive outside school hours care support for children with disability.
- Support groups for families and carers.
- Child and Family Learning Centres
- Online Autism – a fully funded (by the Victorian Department of Health) mandatory professional development training for Maternal and Child Health Nurses in Victoria.

[47] (NDIS, 2022)

- Individual education plans (IEPs) are required for children attending Victorian government schools if the student is supported under individualised funding programs including the Program for Students with Disability and Disability Inclusion. They are highly recommended for students with additional needs. There is little published information about the effectiveness of these plans.
- Revisiting the key worker model that was a central feature of Victoria's Early Childhood Intervention model prior to the NDIS. The key worker coordinated services and the family was engaged in their child's development. This model enables a holistic approach to a child's development and was also intended to ensure interventions are managed for the best outcome for both child and family/carer.
- The pre-NDIS Better Start WA initiative, which assisted children under the age of 7 with certain disabilities for early intervention services. The funding was used to pay for services such as speech pathology, audiology, occupational therapy, physiotherapy, optometry, psychology, orthoptics and services of teachers of the deaf.
- The NSW Disability and Inclusion program, which supports equitable participation n early childhood education programs for children with disability, especially the High Learning Support Needs component.[48]

4.2.2 NDIS Eligibility and Continuity

Carers are anxious about the future of their children's support under the NDIS. The NCN calls for clear communication and safeguards, and for transparency about how new initiatives will interact with the NDIS.

The NCN also recommends the suspension of any rule making around reassessment of children under 9 with autism or developmental delay until Thriving Kids is operational.

The NCN recommends:

17.0 Clarity be provided as to whether the new program will streamline, duplicate or replace current supports, and on the roles and relationships between programs.
18.0 Transparent and independent evaluations be conducted of initiatives designed to support autistic children and those with developmental delay, before they are incorporated into a program such as Thriving Kids.
19.0 Clear communication and safeguards, and transparency about how new initiatives will interact with the NDIS.
20.0 The suspension of any rule making around reassessment of children under 9 with autism or developmental delay until Thriving Kids is operational.

[48] (NSW Department of Education, 2025)

4.3 Identify equity and intersectional issues, in particular, children who identify as First Nations and culturally and linguistically diverse.

Carers have raised experiences in which the assessment and reassessment process for the person they cared for, including autistic children, appeared to have changed. The result of this for these carers was significant cuts to the level of funding for those they cared for, or removal from the Scheme altogether. This has even been seen for children with Level 3 autism.[49]

The NCN would like to reinforce the need for assessments and reassessments for autistic children and adults, and those with permanent developmental delay, to remain consistent with the *NDIS Act 2013* (Cth). Removal of specific disability types from the eligibility criteria, especially without replacement supports in place, risks contravening the Objects and General Principles of the Act. Under these parts of the Act, people with disability and their families and carers, are required to have certainty of lifetime support, access to reasonable and necessary support (inclusive of early intervention) that support their independence, social and economic participation, and that people with disability have the ability to exercise choice and control over support to assist them achieve their goals.[50]

Under the UNCRPD, people with disability must not face discrimination in accessing health, education, community inclusion, or reasonable accommodation.[51] The exclusion of autistic people and those with permanent developmental delay from the NDIS once they are no longer eligible for the Thriving Kids initiative risks breaching Australia's obligations under this convention. Denying these groups ongoing eligibility would effectively exclude them from supports that other people with disability can access, undermining Australia's commitments to upholding the UNCRPD. This is a significant equity issue, as it takes a group of children with a specific disability and shifts them to an alternate scheme with substantially reduced funding.

4.3.1 National Consistency

Significant disparities exist in services and eligibility across states and territories, creating postcode inequity. The NCN would like to see reforms that ensure all families, regardless of location, have equitable access to high-quality supports.

There is concern that reforms, such as the Thriving Kids initiative, could amplify these disparities if foundational supports are delivered through state and mainstream systems without national consistency, further increasing issues such as longer waitlists for assessments and supports.

Regional and remote areas already have widespread shortages of skilled providers, including allied health, paediatricians and therapists. Long waitlists and limited access to specialist services threaten the success of any reform. Investment in workforce development, training and support is needed to ensure providers are equipped to meet the needs of children and families in regional areas.

[49] (Carers WA, 2025)
[50] (Government of Australia, 2025)
[51] (United Nations, 2006)

For carers and families in regional areas, disruptions in continuity of care may be experienced due to service gaps, workforce shortages, and eligibility changes as children age out of programs or move between locations. In these cases, carers will step in to fill service gaps, taking on yet more caring responsibilities and more risk to their own wellbeing.

For example, in Tasmania Child and Family Learning Centres (CFLC), who regularly provide Child Health and Parenting (CHaPs) services, are only accessible to children aged 0 to 5 years, and access in Tasmania is determined by the local government area that the family lives within, removing choice and control over where to access services. Families may not want to access these providers due to privacy concerns, or perceived/actual stigma. Continuity of care challenges also occur once a child ages out of a service, resulting in carers needing to retell the stories of themselves and those they care for repeatedly, which can be traumatising, frustrating and time consuming.

4.3.2 Equity for Disadvantaged and Diverse Families

Children, families and carers from culturally, linguistically, and socioeconomically diverse backgrounds face additional barriers to service access and diagnosis. The NCN calls for targeted strategies, including culturally appropriate services and outreach, to address these inequities.

Special attention should be given to First Nations children and those from CALD backgrounds, with authentic codesign of these services to meet region-specific needs. Examples of services and service gaps raised by NCN members included:

- Children of families who identify as First Nations and culturally and linguistically diverse are less likely to attend early childhood settings, so resources focused on these settings are likely to miss these cohorts.
- Organisations such as the Aboriginal Community Controlled Education, Health and Wellbeing organisations in Victoria provide holistic, wraparound services – but are also likely to be too underfunded to meet actual need.
- In kindergarten settings, some of these services may be funded in different states and territories, but may not be accessible to working parents without sufficient leave to cover school terms. Other families may bring grandparents or other relatives from their home country to mind children while their parents work.
- Parents on low incomes or asylum seekers may access healthcare for their children through low cost or free sources such as emergency departments and community health centres. The staff in these settings must also be upskilled to support parents who are presenting with their children if they are able to identify early signs of developmental delay or autism and refer them to culturally appropriate services for follow up. The Victorian Refugee Health Network is a crucial support for these families as well.
- In Tasmania, health assessment and support services are available through the Tasmanian Aboriginal Health Centre, but to access this service, you must be able to prove that you or your children are of Tasmanian Aboriginal descent.

- Current NDIS eligibility presents limitations to access for children and people with disability who are not yet an Australian citizen or permanent resident, presenting additional barriers to culturally and linguistically diverse people, families and carers. The existing Early connections program does not have these requirements, so it is important that this is not lost in these reforms to ensure access to support for these groups.[52]

The NCN recommends:

21.0 Assessments and reassessments for autistic children and adults, and those with permanent developmental delay, remain consistent with the *NDIS Act 2013* (Cth) (with the application of Recommendation 20 of this submission).

22.0 National consistency within Thriving Kids reforms to ensure all children, families and carers, regardless of location, have equitable access to high-quality supports.

23.0 Investment in workforce development, training and support to ensure providers are equipped to meet the needs of children, carers and families in regional areas.

24.0 Targeted strategies, including culturally appropriate services and outreach, to address inequities faced by children, families and carers from culturally, linguistically, and socioeconomically diverse backgrounds.

25.0 Targeted strategies and authentic codesign of services for children, families and carers from First Nations and CALD backgrounds.

[52] (NDIS, 2024)

4.4 Identify gaps in workforce support and training required to deliver Thriving Kids.

Carers have raised concerns about the availability, capacity and expertise of alternate providers, such as mainstream health, education and other early childcare providers, to adequately support children with autism and developmental delay, their families and carers.

Carers are asking whether there will be enough allied health, early childhood, and school based supports available once demand shifts into Thriving Kids, and how prices, quality, consent, and waitlists will be managed. The policy goal is earlier identification and a national support system - parents and carers want to know it will be staffed and navigated.

Also of concern was whether the workforce, particularly in regional and remote areas, has the capacity and expertise to deliver new supports. Shortages of skilled providers, long waitlists for assessments, and limited access to specialist services threaten the success of any reform. Investment in workforce development, training, and support is needed to ensure providers are equipped to meet the needs of children, families and carers.

The NCN also strongly recommends the Inquiry consider workforce supports for carers, as well as initiatives which enable carers to return to the workforce, as a key prospective workforce resource for the Thriving Kids initiative. This should also include funded peer workers and support roles.

4.4.1 Workforce Capacity and Expertise

"Families like mine need allies to help highlight that:

- *Schools cannot and should not be expected to fill the gap left by reduced NDIS supports.*
- *Removing or limiting therapies takes away opportunities for children to thrive and places more pressure on already exhausted families and carers.*
- *Autistic children are among the most vulnerable groups, and they deserve investment, not further cuts.*
- *Government language and framing around Neurodivergence must be affirming, accurate, and respectful of the autistic community.*
- *Carers need recognition and protection, not more responsibility placed on their shoulders as services are stripped away.*
- *Announcing policy shifts without detail creates unnecessary stress, anxiety, and harm for carers." – feedback from a carer*

The NCN recommends medical and health professionals in all healthcare settings should be given training to support parents and carers and help identify developmental delay and/or autism, noting gender and cultural differences. This includes but is not limited to general practitioners, emergency department and community health centre staff, allied health professionals, maternal and child health nurses, early childhood educators and immunisation providers.

Early Childhood Workers

Announcements concerning the Thriving Kids initiative have raised prospective workforces which could assist with the identification of developmental delay and autism as part of the program, including the early childhood sector.

Putting aside the important and significant focus on child safety reforms which are presently underway in this sector, workers in the early childhood sector are not currently required to have qualifications or training in developmental psychology, paediatrics, speech or occupational therapy. In Carers Tasmania's responses to the Early Years Strategy[53] and the National Child Safety Review[54], they advocated for the need to introduce minimum standards in safety and training as part of the onboarding process. This is a measure which the NCN would also support, especially in the Thriving Kids initiative.

Childcare

The Building Early Education Fund was mentioned in Minister Butler's speech, implying that this could be associated with building employee capacity, however, there is an initial need to increase the number of childcare spaces available, especially in rural and remote areas, to support parents and carers to be able to return to work or obtain employment.

In some regional and remote areas, even standard childcare, outside school hours and vacation care can have long waiting lists or be non-existent. For children with additional needs, these services are often not available in regional, remote or even metropolitan areas. This presents barriers for families and carers to be able to participate in paid employment, social activities or have any break from their caring role.

Some carers are also not able to participate in employment due to their caring role, and may be ineligible for childcare subsidies, resulting in high childcare costs also impacting accessibility.

Specialists

There are significant shortages of therapists, allied health professionals and early childhood specialists. This is especially pronounced in regional and remote areas of Australia.

Examples of initiatives raised by CNC members that could be used to expand access include:

- Tasmanian Child and Family Learning Centres, and Child Health and Parenting Centres, could provide good opportunity to provide support, but differ depending on location. As stated in Carers Tasmania's response to the Foundational Supports Consultation[55], Child and Family Learning Centres, and Child Health and Parenting Centres could help identify significant areas of need and be supported to take a place-based, targeted approach, bringing in paediatricians, occupational therapists and other allied health professionals to their centre for a short, intensive, period of time to provide support to children in that location who are requiring support.

[53] (Carers Tasmania, 2023)
[54] (Carers Tasmania, 2025)
[55] (Carers Tasmania, 2024)

Education Providers

"I wanted to reach out because I'm really concerned about the recent NDIS changes and how they're impacting autistic children and their families. As you know, I have 3 children 2 of whom are Autistic, and from my lived experience across three different schools, it's already clear that schools do not have the resources or capacity to adequately support neurodivergent children. Adding cuts or restrictions to NDIS supports only increases this gap.' – feedback from a carer

Carers have reported challenges in engaging with some education providers to support their children's needs. In some cases, this has led to carers changing schools, or homeschooling has been chosen as the best schooling method for their child's needs. Carers have also raised concerns regarding limited support being available for children being homeschooled.

"where if they were in the school system, the school would be doing an assessment for speech and cognitive and learning. The lady from the Department who came to do my registration said they don't do anything for home-schooling kids.

And then I said to her, ok, it is the DOE, the fact of the matter is, when you pull your child out of school, the department is saving dollars. You move that child out of the school system, it doesn't cost you [department] anything. Why can't they put resources to at least support these families. The numbers are growing with homeschooling. Are these kids going to be ready one day, are they going to be educated enough, some are obviously going to have learning and cognitive disorders that haven't been addressed. All of a sudden, they are adults, and they can't function. I can see a crisis going on. I've been very fortunate because for my daughter and son we have been able to access these support through the NDIS. With my son, I can see the NDIS has done wonders for my son." – feedback from a carer

Feedback from carers is indicative that many education providers do not currently have sufficient resources or capacity to adequately support children with autism or developmental delay. For example, in relation to the current ability of state or territory governments to plan for or meet the needs of students with disability - The NSW Auditor General found in a review of support for students with disability that the NSW Department of Education "does not have a clear and accurate picture of demand compared to supply or the time taken for targeted supports to be provided to students".[56]

The NCN recommends that the Inquiry strongly considers a significant package of support and education for schools if they are to be involved in the Thriving Kids initiative.

In Tasmania currently, there is significant uncertainty across public school settings, with recent industrial action regarding insufficient funding and support. Fair, adequate, and sustainable funding models across all Australian schools must take a strong focus alongside the Thriving Kids Initiative.

[56] (Audit Office of New South Wales, 2024)

The NCN recommends:

26.0 Investment in workforce development, training, and support to ensure providers are equipped to meet the needs of children, families and carers in the Thriving Kids initiative.

27.0 The Inquiry considers workforce supports for carers, as well as initiatives which enable carers to return to the workforce, as a key prospective workforce resource for the Thriving Kids initiative. This should also include funded peer workers and support roles.

28.0 The NCN recommends medical and health professionals in all healthcare settings should be given training to support parents and carers and help identify developmental delay and/or autism, noting gender and cultural differences.

29.0 Introduce minimum standards in safety and training as part of the onboarding process for early childhood workers.

30.0 Childcare spaces in regional and remote areas be increased.

31.0 The availability of childcare, vacation care and outside school hours care for children with additional needs be significantly increased.

32.0 Initiatives are implemented to expand access to therapists, allied health professionals and early childhood specialists, including in regional and remote areas.

33.0 The Inquiry include a significant package of support and education for schools if they are to be involved in the Thriving Kids initiative. Fair, adequate, and sustainable funding models across all Australian schools must take a strong focus alongside the Thriving Kids Initiative.

4.4.2 Workforce support for carers

'Most carers I know have lost fulfilling careers, have limited superannuation, and quite simply cannot afford many of the things that non-carers can. My future and the futures of my carer friends quite frankly look very bleak. Personally, I would love to be in the workforce and I'm currently trying to start my own business to try and generate some income. How I can fit this in alongside my caring role I have no idea but I'm fearful for my future and future security. I certainly won't have children who have any capacity to look after me if I become ill or when I'm old. Words mean very little. Carers don't need words we need support which meaningfully and positively impacts our carer role and provides us with security'. – response from a carer.

In a survey of WA carers to inform CAWA's response to the Inquiry into Carer Recognition,[57] 77.23% of carers responded that it was important or very important to them to be recognised in the workplace. In the same survey, 77.45% of carers reported it was important or very important to be recognised in educational facilities. In addition to recognition, carers need support and flexibility within these settings to be able to partake in paid work, study or preparing to take on these extra commitments on top of their caring role. Carers are an untapped workforce who if properly supported, can contribute to filling some of the workforce gaps which will arise in the Thriving Kids initiative.

Job Readiness/non-workplace focussed employment support

Carer-specific job readiness programs, such as Carers WA's Be Job Ready Program, play a key role in helping carers to upskill, and connect to employment and education opportunities. This is particularly important when carers have been out of the workforce for a long time due to their caring role, during which time job hunting processes have drastically changed, but carers have also gained new skillsets through their caring experience. Job readiness programs can also help carers to identify and utilise these new skills. However, despite the benefits of these programs, funding for them lacks continuity and is only for short periods of time.[58]

The projected average lifetime cost for people on the Carer Payment is $592,000[59]. This is the saving to government for every carer who returns or enters the workforce and who is no longer on the carer payment. Add to this other savings such as this person's reduced need for the age pension due to having built up superannuation; the increase to their mental and physical wellbeing that participation in paid work brings carers; etc. Continuity of funding and increased capacity for job readiness programs for carers is a measure which makes economic sense.

Carer Friendly Workplaces

The Australian Government Productivity Commission's Inquiry into Carers Leave found that flexible working arrangements are highly valued by carers and form a key factor to carers being able to manage their paid work and caring commitments.[60]

[57] (Carers WA, 2023)
[58] (Carers WA, 2024)
[59] (Department of Social Services, 2022)
[60] (Australian Government Productivity Commission, 2023)

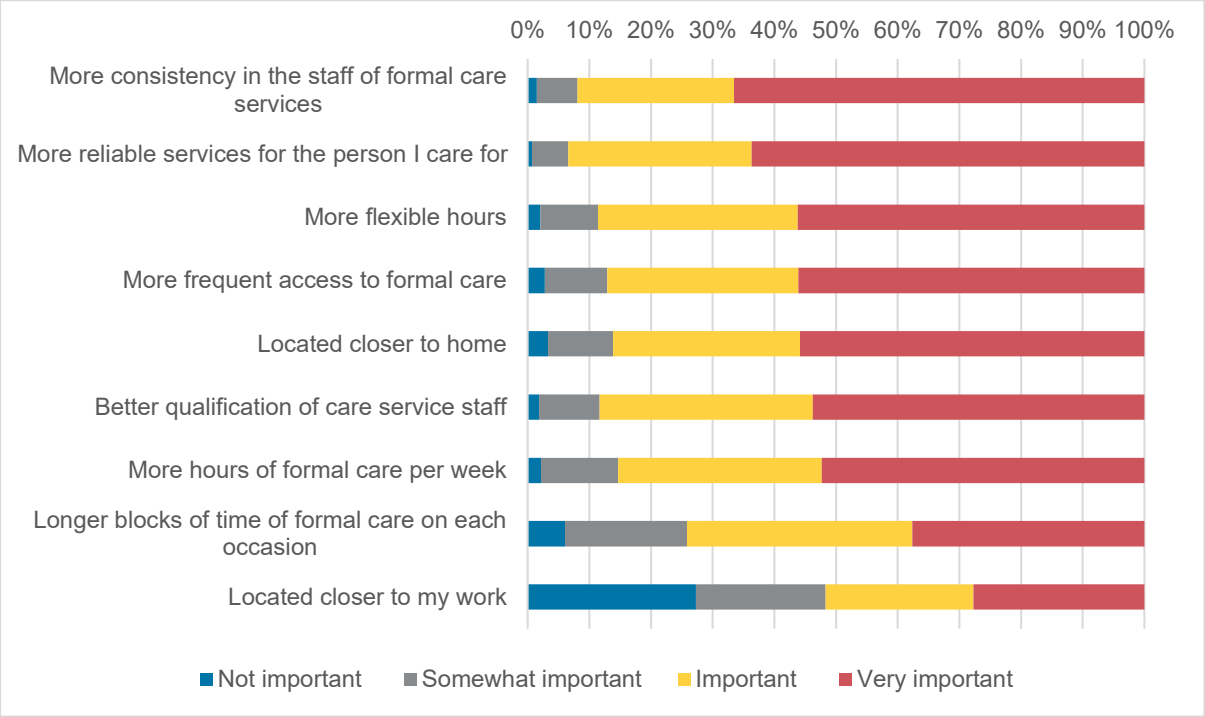
When carers are not able to access suitable flexible working arrangements, carers reduce their engagement with the paid workforce, resulting in limited income and opportunities for career advancement. Subsequently, carers' long term financial security, health and wellbeing is impacted[61]. Paid work provides carers with a mechanism to achieve financial security, social connection, and a meaningful activity. The 2022 National Carer Survey[62] found that 74.7% of respondents felt that paid work provides them with important social connections outside of caring, and 82% reported it provides a sense of purpose[63]. Hence, reducing barriers to carers maintaining and re-entering paid work are essential to not only carers' financial security, but also their health and wellbeing outcomes.

The barriers which prevent carers being able to participate in paid work, include care intensity; access to care services; and workplace flexibility. Carers, on average, report spending over 100 hours a week per carer caring, with the 2024 National Carer Survey finding that 50.7% of carers providing 24/7 care[64]. This restricts a carer's ability to work more than part-time, or even work at all. Over half of carers (53%) also reported being a sole carer for someone in the 2024 Survey, relying heavily on formal services to have the time to work. Carers also often seek to work in flexible jobs and industries to be able to work flexibly, which may include things such as varying start and finish time or working from home[65]. The 2022 National Carer Survey found that while 57.7% of carers reported having access to flexible working arrangements, 1 in 2 carers were not satisfied with their work-life balance and 49.7% of carers did not have enough paid leave required for their caring role[66]. Carers have also reported that their limited ability to engage in paid work has impacted their career progression, leading to lower income potential and superannuation[67].

Furthermore, the 2024 National Carer Survey explored barriers to employment associated with access to formal care services. Carers of children living with autism and developmental delay 0-8 who responded to the Survey reported that the most important change to support work care balance was the services available to support the person they care for. In regard to changes to formal services that would support employment, these respondents identified the three most important changes as more consistency in the staff of formal care services, more reliable services and more flexible hours of care services (Figure 1.).[68]

[61] (Carers NSW, 2023)
[62] Questions not asked in Carers NSW 2024 National Carer Survey.
[63] (Carers NSW, 2023)
[64] (Carers NSW, 2025)
[65] (Carers NSW, 2023)
[66] (Carers NSW, 2023)
[67] (Carers NSW, 2023)
[68] (Carers NSW, 2025)

Figure 1. Changes to formal care services that would support carers of children living with disability aged 0-8 to balance work and care[69]



Carers who do participate in paid work have reported on the importance of recognition, understanding and support from managers – all of which have a positive impact on job satisfaction and retention. More than half of carers reported choosing an employer due to being able to access flexible working arrangements[70].

[69] (Carers NSW, 2025)
[70] (Carers NSW, 2023)

4.5 Domestic and international policy experience and best practice

The NCN recommends that the Thriving Kids initiative align with human rights standards such as the UNCRPD[71] and UNCRC[72], as well as carers rights standards as outlined in the *Carer Recognition Act 2010* (Cth) and Schedule for Australia's Carers.[73]

The NCN also calls for the Thriving Kids initiative to align with and embed practices as seen in key strategies such as the National Autism Strategy, the Early Years Strategy, the National Carer Strategy and Action Plan, Australia's Disability Strategy and National Action Plan for the Health of Children and Young People 2020-2030.

Where there is a state or territory focus on aspects of the Thriving Kids initiative, this should also align with relevant Carer Recognition Acts, as well as other relevant legislation, policies and standards within each state and territory.

Best practice and evidence-based support for carers

Best practice includes authentic collaboration, development, and monitoring with and by autistic individuals and those with developmental delay, as well as their families and carers. A thorough and robust evaluation framework is recommended to be developed and utilised to assess the effectiveness of the Thriving Kids Initiative, delivering continuity of care, neuro-affirming support, and facilitate positive outcomes for children, their families and carers.

The NCN recommends:

34.0 The Thriving Kids initiative align with human rights standards such as the UNCRPD and UNCRC, as well as carers rights standards as outlined in the *Carer Recognition Act 2010* (Cth) and Schedule for Australia's Carers.

35.0 The Thriving Kids initiative align with and embed practices as seen in key strategies such as the National Autism Strategy, the Early Years Strategy, the National Carer Strategy and Action Plan, Australia's Disability Strategy and National Action Plan for the Health of Children and Young People 2020-2030.

36.0 Where relevant, the Thriving Kids initiative should also align with relevant Carer Recognition Acts, as well as other relevant legislation, policies and standards within each state and territory.

37.0 Development of a robust and thorough evaluation framework to assess the effectiveness of the Thriving Kids Initiative, delivering continuity of care, neuro-affirming support, and facilitate positive outcomes for children, their families and carers.

[71] (United Nations, 2006)
[72] (United Nations, 2025)
[73] (Commonwealth of Australia, 2010)

4.6 Mechanisms to allow a seamless transition through mainstream systems for all children with mild to moderate support needs

Presently, mainstream service systems in many states and territories are not sufficiently resourced to support children with autism or developmental delay, or their families and carers. Schools and outside school hours services are not equitable or sufficiently resourced for current requirements, or for the increased requirements of the Thriving Kids initiative. Public and private health and mental health settings are not always neuro-affirming, and there are significant workforce shortages, waitlists and healthcare affordability issues.

Further, services are difficult for families and carers to navigate; transition between services or at times of transition can be difficult to transverse; and there is widespread misunderstanding or limited understanding of autism and the caring role. In addition, many details about the Thriving Kids initiative are not clear, including the definition of 'mild to moderate' support needs – presenting difficulties in identifying transition initiatives when services that will be involved are not well-defined.

4.6.1 Transition support for carers

'Appropriate acknowledgement, which is then practically demonstrated in actual needed support, and not just financially but also in regards to carer health and wellbeing and importantly with navigating the system (as we are dealing with multiple 'households' and everything associated with them - our own and the person we care for). Timely access to services, more efficient and streamlined processes, information in one spot (the amount of times I've had conflicting info or been provided with info on services from other people that is not obvious on any website anywhere), better access to respite care. All of this assists the carer continue with working as well - this for me is my sole income (I have no other family support).' – response from a carer

Carers report widespread difficulties in trying to traverse the maze of services they must access for themselves and those they care for, with some carers simply giving up trying to do so due to the effort and exhaustion this process causes. In regional and remote Australia, this issue is even more pronounced due to limited availability and affordability of services, and ongoing workforce issues. Often, limited awareness of available services further increases the task of being able to find services. This issue has the impact of carers and those they care for either not being able to access services or have the task of accessing services become a full-time job to maintain them. This is a task which carers will often take on, and one which has a significant impact on carers being able to return or enter into paid work due to its time requirements. In addition, the stress of trying to access services has adverse impacts on carers' health and wellbeing.[74]

The NCN recommends transition and service access support for carers and families be considered as part of the Thriving Kids program.

[74] (Carers WA, 2024)

4.6.2 Other initiatives for transition

Carers have raised concerns regarding the Thriving Kids initiative, and when the program commences, families and carers are likely to be concerned regarding any prospective transition between programs for their children.

The NCN recommends the following measures to assist in this transition:

- Funded lived experience/peer workers to help with the transition between services.
- Any staff member who is transitioning families to undergo trauma informed training, as well as training in carer, disability, neurodiversity and cultural competency awareness training.

Other measures the NCN would like to raise for consideration include:

- Investment into schooling, outside school hours care, health (including allied health) and mental health.
- Expansion of the Disability Standards for Education to include outside school hours care, with national consistency in funding and programs to increase equity.
- Ensuring all states and territories have Autism Strategies, as well as funded peak bodies for autism and developmental delay.
- The Thriving Kids Initiative supports and allows for seamless access into mental health services, underpinned by the National Roadmap to Improve the Health and Mental Health of Autistic People.
- Utilisation of the different interfaces (many already health oriented) to support parents including infant/childhood immunisation, emergency department presentations and community health settings.
- Utilise other community spaces such as libraries and mothers' groups to raise awareness and reduce stigma.
- Allow varied referral pathways to avoid bottlenecks in general practice.
- Substantially reduce out-of-pocket costs for assessment and ongoing therapies, including no-gap Medicare rebates for allied health services.

The NCN recommends:

38.0 Transition and service access support for carers and families be considered as part of the Thriving Kids program.

39.0 Any staff member who is transitioning families between services to undergo trauma informed training, as well as training in carer, disability, neurodiversity and cultural competency awareness training.

40.0 Appropriate resourcing for all services involved in the Thriving Kids initiative.

41.0 Transition and referral pathways between all services and touch points.

42.0 Expansion of the Disability Standards for Education to include outside school hours care, with national consistency in funding and programs to increase equity.

4.0 Conclusion

The members of the National Carers Network look forward to partnering with government to assist with the development and implementation of a Thriving Kids program which achieves the best outcomes for children, their families and carers.

We have reinforced the need for increased clarity and consultation with these groups at all stages of project design and delivery, and are keen to work with government to help facilitate these connections with Australian carers. Also raised has been a range of key challenges to consider and overcome in collaboration with stakeholders, and opportunities for system reform in the process.

Should any further information be required regarding the comments included within this submission, or assistance from the perspective of Australian carers, the National Carers Network would be delighted to assist. Please contact the Carers WA Policy Team at policy@carerswa.asn.au.

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