

**INQUIRY INTO FOUNDATIONAL AND DISABILITY  
SUPPORTS AVAILABLE FOR CHILDREN AND YOUNG  
PEOPLE IN NEW SOUTH WALES**

**Organisation:** Carers NSW

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Select Committee on Foundational and Disability Supports Available for Children and Young People  
in New South Wales  
Legislative Council  
NSW Parliament House  
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**Carers NSW submission to Select Committee on Foundational and Disability Supports  
Available for Children and Young People in New South Wales**

Carers NSW thanks the Select Committee on Foundational and Disability Supports Available for Children and Young People in New South Wales (the Committee) for the opportunity to respond to consultation regarding disability supports for children living with disability in NSW. This brief submission will draw largely on concerns previously raised by Carers NSW in consultations facilitated by the Australian and NSW Governments about the proposed Foundational Supports model as well as the disability service system more generally.

Carers NSW is the peak non-government organisation for carers in New South Wales (NSW). A carer is any individual who provides care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail. Carers NSW is part of the National Carer Network and a member of Carers Australia. Our vision is an Australia that values and supports all carers, and our goals are to:

- Be a leading carer organisation in which carers have confidence
- Actively promote carer recognition and support
- Actively support carers to navigate a changing service landscape that will be characterised by ongoing policy reform
- Promote connected community experiences and opportunities for carers that are inclusive of diverse carer groups
- Lead and advocate for carer-specific and carer-inclusive policy making, research and service delivery
- Continue to be a quality-driven, responsive and carer-focused organisation.

Thank you for accepting our submission. For further information, please contact Grace Cherrington, Policy Officer

Yours sincerely,

Elena Katrakis  
CEO  
Carers NSW

## Introduction

Carers NSW thanks the Committee for the opportunity to respond to its inquiry into foundational and general disability supports for children living with disability in NSW. Data from the 2022 Survey of Ageing, Disability and Carers indicates that there are approximately 518,600 children and young people aged 0-14 years living with disability in Australia.<sup>1</sup> SDAC data also estimates that there are approximately 430,200 young people aged 15-24 living with disability.<sup>2</sup> Carers NSW recognises the unique role parents and families play in the lives of children and young people living with disability, even where formal services exist.

While Carers NSW welcomes consultation on identifying and exploring known gaps in the disability service system, particularly for children living with disability, many of these concerns have been raised repeatedly at both a state and federal level through consultations attached the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Royal Commission), the NDIS Review and Australia's Disability Strategy. Carers NSW has also utilised consecutive NSW Pre-Budget Submissions to highlight the ongoing policy gaps for people living with disability and their carers since the rollout of the NDIS. Finally, Carers NSW draws reference to the Briefing paper – *Foundational and disability supports available for children and young people in New South Wales*, published by the Committee which draws together findings from the abovementioned government consultations and provides a comprehensive overview of many of the current identified issues and gaps for children and young people living with disability, their families and carers.

This inquiry exists during a time where significant changes to the disability service system are anticipated to occur. With initial rollout of Foundational Supports slated to begin from mid-2025 (and before the Committee is due to report back to government), we believe this inquiry would be better placed to raise concerns regarding the lack of information to date regarding this rollout, as well as provide further opportunity for NSW-based stakeholders to critique what is known about the proposed Foundational Supports model and how this is likely to be articulated in a NSW service context.

To that end, this submission will respond to elements of the Terms of Reference we believe are most relevant to the broader reform currently underway and the likely impact this will have on family and friend carers supporting a child living with disability.

## Understanding the disability service system in NSW

In NSW, disability supports have been provided almost exclusively through the NDIS since its full rollout in 2017 with limited alternative disability-specific supports available to those who are unable to access the Scheme. Where service gaps have emerged, people living with disability have either been excluded from mainstream services and supports or have relied on support from family or friend carers to support their participation in education, work or their community more broadly. This has happened despite clear obligations under various state and federal anti-discrimination legislation for mainstream services and supports to be inclusive and accessible. Carers NSW has written at length regarding the emotional and economic impacts of gaps in disability supports on carers and the people they care for since the roll-out of the NDIS, particularly as this has created an increased reliance on carers to fill gaps in support.

Carers NSW has made repeated calls for the NSW Government to fund additional, alternative disability support services for those who would otherwise be ineligible for the NDIS. While Foundational Supports seek to address and fill these longstanding service gaps, we are concerned that the unique service landscape of each state and territory is not fully understood. While some states and territories may continue to fund existing disability services in addition to Foundational Supports, there will be others like NSW where service gaps are likely to persist.

While some concerns regarding disability support have been addressed through the proposed Foundational Supports model, we believe that the current model will not adequately meet the needs of the approximately 4.8 million Australians living with disability who do not receive support through the

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<sup>1</sup> Australian Bureau of Statistics (2024) Survey of Ageing, Disability and Carers 2022, TableBuilder Dataset, available online at: [www.abs.gov.au](http://www.abs.gov.au)

<sup>2</sup> ABS (2024)

NDIS.<sup>3</sup> Carers NSW acknowledges this inquiry is focused on the experiences of children living with disability and their unique needs but wishes to emphasise the importance of holistic disability support for all people living with disability, irrespective of their age. Carers NSW also notes that the current model of Foundational Supports does not adequately address points of transition for children and young people living with disability who may 'age out' of dedicated services through Foundational Supports with limited ongoing supports. Though the proposed model indicates adults living with disability will receive some practical support through Foundational Supports, Carers NSW remains concerned that family and friend carers will continue to fill service and support gaps, especially if all other formal service options are exhausted.

### **The role of diagnostic services, existing gaps and barriers, and measures to improve effectiveness, availability and access of such services**

Carers NSW is pleased to observe the Committee's interest in understanding the specific concerns related to the role and availability of diagnostic services, as well as the implications where such services cannot be accessed.

It is well established that to be found eligible for the NDIS, children and people living with disability are required to provide evidence of their disability. Such evidence is often acquired through various diagnostic assessments conducted by multidisciplinary teams, ranging from specialist doctors like paediatricians, to allied health professionals including speech pathologists, occupational therapists, psychologists and other clinicians.

While such assessments can be accessed through the public health system, anecdotal evidence indicates that wait-times for these services can be up to 2-3 years in some areas of NSW. Where people living with disability and their carers cannot access state-subsidised diagnostic services, they are often required to engage privately funded clinicians at significant personal cost or provide informal care in their place, sometimes unsustainably, until publicly funded services become available.

Carers NSW recognises the work undertaken by the National Disability Insurance Agency (NDIA) to address barriers and access to diagnostic assessments through the proposed needs assessment, where support needs will be assessed independently through the Agency, without any cost to the participant, their families and carers. At a state level, the NSW Government has also announced further investment in the public paediatric allied health workforce to reduce waitlists and improve access to diagnosis and therapy for children across NSW, including those in rural and remote communities.

While each of these initiatives demonstrate an understanding of the impact of barriers to diagnosis, as well as a commitment from state and federal governments to address them, Carers NSW believes that their effectiveness will likely be reduced due to ongoing workforce concerns in the care and support economy.

Carers NSW has written several submissions responding to inquiries led by Jobs and Skills Australia,<sup>4</sup> and the Joint Standing Committee on the National Insurance Scheme.<sup>5</sup> In each of these submissions we have highlighted the continued impact of workforce shortages; the effect it has on essential services and supports, and the sustainability of care relationships where formal supports cannot be accessed.

### **Ensuring the Foundational Supports address the unmet needs of carers**

Carers NSW has previously raised concerns with the NSW Government about the reduction in supports available to carers of people living with disability following the roll-out of the NDIS. Prior to the introduction of the NDIS, a number of NSW and Australian Government funded disability support programs also provided carer-focused support such as respite for carers of people living with disability. Many of these programs were ceased following the roll-out of the NDIS, with funding for these programs

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<sup>3</sup> This figure is based on data from the Australian Bureau of Statistics, Survey of Disability Ageing & Carers 2022 dataset and total participants as recorded in the National Disability Insurance Scheme Quarterly Report Q2 2024-25

<sup>4</sup> (2023) Carers NSW, Carers NSW Submission to the Department of Employment and Workplace Relations in response to the Jobs and Skills Australia Discussion Paper. North Sydney 2060.

<sup>5</sup> (2021) Carers NSW, Carers NSW submission to Joint Standing Committee on the National Disability Insurance Scheme (NDIS) on NDIS Workforce. North Sydney 2060.

redirected to support the implementation of the NDIS.<sup>6</sup> For the many carers of people living with disability who are ineligible for the NDIS, this resulted in a reduction in supports that meet their own needs.<sup>7</sup> While the introduction of Carer Gateway has addressed some of these gaps, carers of people living with disability continue to report unmet needs for disability-specific service navigation, education and capability building, and planned, ongoing respite, supports not in scope for Carer Gateway.

Carers NSW believes that the establishment of Foundational Supports provides an opportunity for the re-establishment of targeted supports for carers of people living with disability in NSW. As such, Carers NSW strongly encourages the NSW Government to advocate for the inclusion of carer-focused supports, especially ongoing, planned respite, within the development of Foundational Supports. This is to ensure that services and supports for carers of people living with disability in NSW that were reduced or lost as a result of the introduction of the NDIS can be re-established and expanded to meet carers ongoing unmet needs.

For carers of children and young people living with disability, Carers NSW is particularly concerned about the limited information available about the specific supports they will receive through Foundational Supports. While previous consultation opportunities attached to Foundational Supports suggest families and carers will receive capacity-building support to adequately understand and navigate the disability service system, there has been minimal indication as to whether they will receive practical supports.

As raised in our submission responding to the Department of Social Services (DSS) consultation on General and Targeted Foundational Supports, Carers NSW has become increasingly concerned that practical supports are not in scope for people living with disability not receiving support through the NDIS. Carers NSW is particularly concerned for carers of children and young people living with disability who have historically received comparatively less practical support via formalised disability services since the roll out of the NDIS due to perceptions of 'parental responsibility'. While General Supports will certainly meet the service needs around peer support, system navigation and individual and sector capacity building, without dedicated practical support available for all people living with disability, we anticipate significant unmet need for people living with disability and their carers to remain if not worsen.

## Conclusion

Carers NSW thanks the Committee for the opportunity to contribute to the inquiry on Foundational and Disability Supports Available for Children and Young People in New South Wales. Carers NSW acknowledges the importance of this inquiry but emphasises that many of the issues identified have already been extensively documented through previous consultations and reports. With the rollout of Foundational Supports fast approaching, this inquiry presents a timely opportunity to address the lack of clarity around implementation and ensure NSW stakeholders can meaningfully engage with the proposed model.

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<sup>6</sup> Carers NSW on behalf of the Carer Respite Alliance (2021) *Repositioning respite within consumer directed service systems*, available online at: <https://www.carersnsw.org.au/uploads/main/Files/5.About-us/News/Repositioning-respite-within-consumer-directed-service-systems.pdf>.

<sup>7</sup> Ibid.