

23 August 2024

NDIS Consultations
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Carers NSW welcomes the opportunity to provide a submission to the Department of Social Services (the Department) in response to the draft list of NDIS Supports. Carers NSW believes that the NDIS Review and associated reforms provide a significant opportunity to improve the disability supports available to people living with disability, their families and carers. However, we believe that greater focus on enabling and improving support for carers must be embedded within reforms. Additionally, we would like to highlight concerns about the short consultation period for this matter which may have limited the ability of carers and the NDIS participants that they care for to participate.

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 Melissa Docker, Senior Policy and Development Officer at melissad@carersnsw.org.au or on (02) 9280 4744.

Yours sincerely,



Elena Katrakis
CEO
Carers NSW

Introduction

Carers NSW welcomes the opportunity to respond to this consultation and recognises the significant opportunity to address a number of long-standing issues with the National Disability Insurance Scheme (NDIS) through the development of a new NDIS Bill.

While the NDIS has been transformative for people living with disability, their families and carers, Carers NSW understands that for many family and carers, a lack of appropriate recognition and inclusion within the NDIS has created unique challenges for both their caring role and their own individual support needs. As such, Carers NSW believes that current review of NDIS funded supports should not only aim to create clarity and consistency in regard to supports that can and cannot be funded under the NDIS, but also create greater clarity around supports for family and carers that can be funded under the NDIS where these supports align with the goals of and enable improved outcomes for NDIS participants.

Background

Carers NSW believes in the importance of autonomy and self-determination for people with disability and is supportive of policy and practice that facilitates their independence and meaningful participation in community life. Carers NSW has fully supported the transition towards more person-centred approaches to service delivery for people living with disability and believes this human rights approach to disability support continues to enable people living with disability and their families and carers to have more choice and control over their life and wellbeing, including their inclusion and participation in society.

Carers NSW acknowledges that not all people living with disability receive informal support or would identify with having a 'carer'. However, current data captured by the Australian Bureau of Statistics (ABS) indicates that approximately a majority of people living with disability in Australia who needed assistance receive this from informal supports,¹ just over half required this assistance and support on a daily basis.² People living with disability needing assistance were most likely to receive informal support with communication, mobility, and reading or writing tasks.

Carers often provide significant support to the person(s) they care for; from support with nutrition through provision of shopping and assistance with meal preparation, to support with employment and income security, through provision of practical support with administration and finances, and support with decision making. Carers also often support the people they care for to access specialised and mainstream services and supports, such as the NDIS supporting with service navigation, coordination of supports and advocacy. The support provided by carers is complex and varied, influenced by the caring relationship, the care recipients' preferences, needs and rights, and factors such as culture, socio-economic status, geographic location, and other such demographic influences.

Carers NSW believes that given the invaluable role of carers in the lives of their family member or friend living with disability, appropriate consideration should be given to improving service experiences and support for carers in the design and implementation of disability support. This also aligns with Australia's Disability Strategy 2021-2031, *Policy Priority 3: The role of informal support is acknowledged and supported of Outcome Area: Personal and Community Support*.

Recognising and supporting carers through the NDIS

Carers NSW has significant concerns that there is limited reference to supports for family and carers, such as respite or supports aimed at building the capability of carers to provide care to NDIS Participants, within the draft list of NDIS supports. Carers often play a significant role in the network and

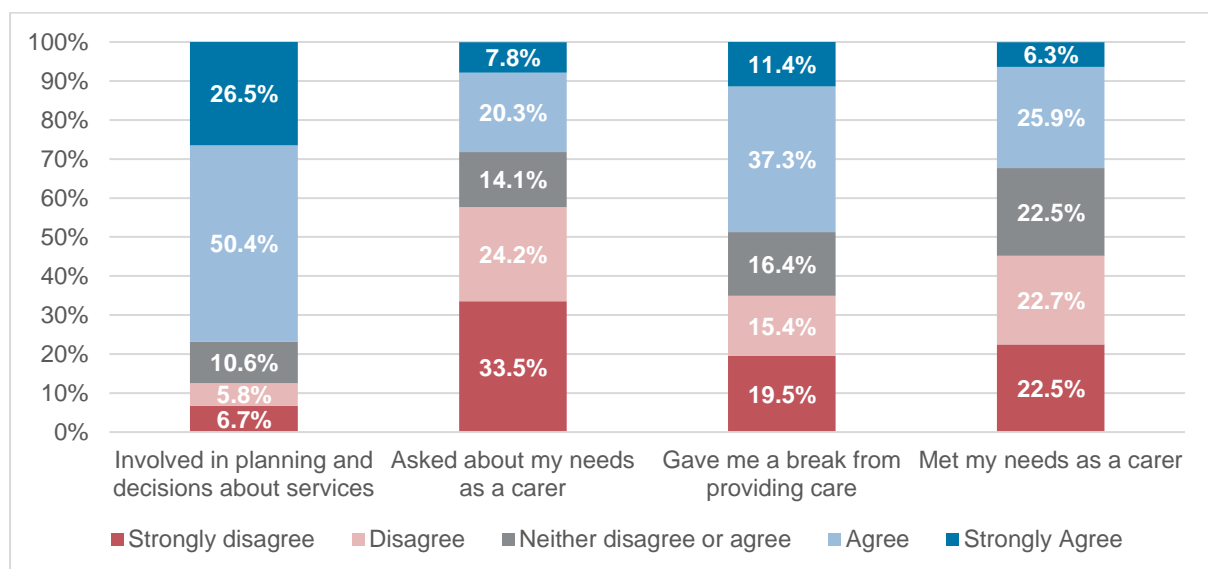
¹ Australian Bureau of Statistics (2024) *2022 Survey of Disability, Ageing and Carers*, available online at www.abs.gov.au.

² Ibid.

continuum of supports of people with disability, complimenting NDIS services and reducing reliance on formal supports. However, many carers report to Carers NSW that they are not recognised or included in the planning and delivery of NDIS services and supports. Where carers are included, their needs are often not considered or addressed, even where these needs intersect with those of the person they care for. This often results in NDIS plans that do not include adequate funding for support aimed at enhancing or sustaining informal caring arrangements, such as carer education and training and regular breaks from the caring role or respite.

Carers NSW 2022 National Carer Survey found that of respondents who provided support to somebody accessing the NDIS, 1 in 8 were not included in planning and decisions about services and more than half (57.5%) were not asked about their needs as a carer. Subsequently, almost half (45.2%) reported that services did not meet their needs and approximately 1 in 3 (34.9%) reported that services did not provide them with a break from providing care.

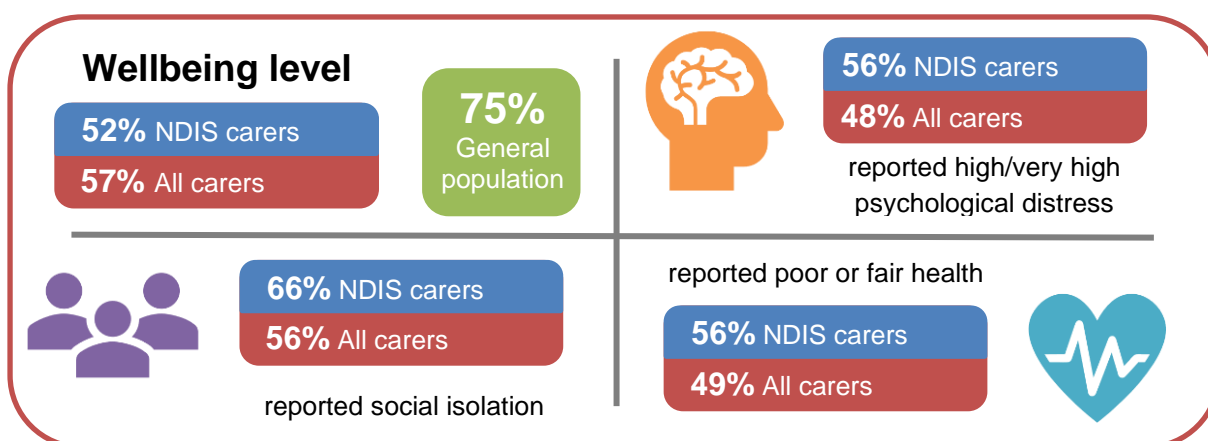
Figure 1. Carers’ experiences engaging with NDIS supports³



Where carers are not included in planning and decisions about services or their needs are not considered or met, this can have significant impacts on their health and wellbeing. The 2022 National Carer Survey found that compared to the whole sample, carers supporting someone accessing NDIS services and supports reported lower wellbeing, higher psychological distress, greater social isolation and poorer health outcomes (Figure 2).

³ Carers NSW (2022) *National Carer Survey, Unpublished data.*

Figure 2. Health and wellbeing outcomes for carers of persons with disability under 65 accessing NDIS compared to whole sample.⁴



Embedding carer-focused supports within the NDIS

Carers NSW has significant concerns that the newly proposed draft NDIS Supports list is not clear enough in articulating the inclusion of supports aimed at building the capacity of family and carers to provide care or maintain informal caring arrangements, such as respite and capability-building supports. While Carers NSW recognises that these supports often fall under other types of eligible NDIS supports that enable people living with disability to live and be included in the community across different domains, concerns remain that where supports for carers that align with participant goals are not explicitly stated, there remains confusion around whether they can be funded under the scheme and as such are less likely to be considered or included in NDIS plans and budgets.

This was previously evidenced by the initial decision to exclude the term “respite” from the NDIS Price Guide when the NDIS was rolled out. Following this decision, many carers reported to Carers NSW that they were advised by NDIS staff and Local Area Coordinators (LACs) that respite was not able to be funded through the NDIS. The re-introduction of the term “respite” to the NDIS in relation to Short Term Accommodation (STA) has seen increased inclusion of this support type, however carers report that they are still unable to access other forms of respite, such as in-home respite, that provide meaningful breaks from the caring role for the participant and carers as these are not explicitly included service categories. While Carers NSW acknowledges that the draft NDIS Supports list does make note of respite in relation to Assistance with Daily Life Tasks in a Group or Shared Living Arrangement, there is concern that the specific inclusion under only this category will reinforce confusion around the funding of respite for carers outside of STA.

In order to ensure the long-term sustainability of informal caring arrangements, Carers NSW believes that the new NDIS Supports list must be reviewed to ensure that supports for carers are explicitly included under their own support type, especially those that aim to enhance and sustain informal caring arrangements and relationships and support the overarching goals of NDIS participants. Explicit inclusion of these supports will ensure clarity and consistency for NDIS participants and their carers.

Conclusion

Carers NSW again thanks the Committee for the opportunity to respond on this important matter. The design and implementation of the NDIS has been transformative for many people with disability, their families and carers and Carers NSW wishes to acknowledge the work of the Australian Government and NDIA over recent years to improve participant and carer experiences of the NDIS. Carers NSW

⁴ Carers NSW (2022).

believes that this Bill provides a timely opportunity to embed greater and recognition and support for carers within the NDIS to improve the outcomes and experiences for people with disability, their families and carers. However, Carers NSW believes that far greater detail and consultation is needed in the development of the Act and associated rules and legislative instruments to support ongoing confidence and trust in the Scheme.