

Carers Victoria Submission to the National Disability Insurance Scheme Review, 2023

Executive Summary

Carers Victoria welcomes the opportunity to make this submission to the National Disability Insurance Scheme Review (the Review). For many Australians living with disability, the introduction of the National Disability Scheme (NDIS) has been transformative and Carers Victoria strongly supports the fundamental tenets of choice and control that underpin that Scheme.

People in care relationships with people with disability comprise a significant number of unpaid carers, including NDIS participants, and survey data suggests that some 65% of those carers provide more than 60 hours of support a week. This means that the assistance they provide frequently outstrips that provided via funded supports, and highlights that they are a "mission critical" component of the ecosystem for many NDIS participants.

We were thus disappointed to note that while the interim Report *What we have heard: Moving from defining problems to designing solutions to build a better NDIS June 2022* included some positive interim findings, it did not contain any specific references to the unpaid carers of NDIS participants.

Sadly, this reflects what many Victorian carers tell us - that while they play a significant role in supporting NDIS participants, they currently feel overlooked, unsupported and in many instances, disregarded by the Agency and other government funded entities.

The Review offers an important opportunity to remedy this, by tackling some of the main limitations of the Scheme identified by carers. This submission shares a set of carer perspectives on the current Scheme, and sets out some opportunities to enhance current arrangements by:

- Simplifying assessment and planning processes to reduce the time and resources required by carers to support participation in the Scheme,
- Ensuring the capacity, needs and intentions of carers are regularly assessed, and
- Ensuring that carer needs can access the support they need to sustain them in their role;

The Review also offers an opportunity to enhance the overall design and operation of the Scheme into the future, by recognising and embedding the often unique perspectives and expertise that those in caring roles have developed through their interactions with both the Scheme and its interface with mainstream services. Incorporating carer perspectives into design and review activities has the potential to enhance overall system effectiveness by highlighting opportunities for improvement - without compromising individual participant choice and control.

Carers Victoria is pleased to have this opportunity to contribute to the Review. We believe the prospective changes to the NDIS highlighted in this submission will ensure unpaid carers are able to sustain their important role in supporting strong outcomes for participants. While this submission is provided at a high level, we are happy to supply the Review with any additional detail that may assist.

We are particularly keen to see these changes progressed because we believe that without them, there is a significant risk that into the future, there will be more unpaid carers who are unable to

sustain the role long term. This not only would result in poorer outcomes for participants and the people who have been providing that care but runs the risk of exacerbating pressures on Scheme at a time where government is seeking to enhance its sustainability.

Carers Victoria, alongside other members of the National Carers Network, looks forward to contributing to a future Scheme that both delivers on the aspirations of its participants but does not leave carers behind.

Indeed, the interests of both participants align much more often than not, and by focusing on the key members of the care relationship rather than just the participant, there is much greater potential to achieve a sustainable and effective Scheme that delivers for participants, carers, and the broader community: a powerful aspiration that we can achieve together.

About Carers Victoria

Carers Victoria is the state-wide voice for unpaid carers in Victoria. It provides a wide range of services and programs to support Victorian carers in their lives and caring roles.

Carers Victoria provides a range of other assistance to carers including opportunities for connection through events, education, and networks; provision of information and advice curated to meet the needs and interests of carers; access to funded respite; and other opportunities to improve social connectedness.

It also gives carers an opportunity to have their voice heard through policy and advocacy activities that are informed by what carers tell us matter to them, with Carers Victoria both developing its own Victorian-specific submissions and contributing to national submissions via the National Carer Network.

For further information in relation to the content of this submission or issues arising, please contact Mr Nick Orchard, General Manager Policy and Transformation at Carers Victoria via email, nick.orchard@carersvictoria.org.au.

What do carers tell us about their experiences?

Lived experience of carers, like the lived experience of people living with disability, is fundamental to shaping an effective future system.

Carers Victoria supports a wide range of unpaid carers, a significant number of whom are supporting one or more NDIS participants. The following are a selection of quotes that speak to individuals lived experience of being in a care relationship with a NDIS participant, and their experiences of the current Scheme.

"Some days it's exhausting and you can't even breathe because you have so much responsibility. We do get funding for the NDIS but that's only for the kids and their therapy; but as a carer, I don't. We don't have any family in the country. It's a struggle when you don't have any support for you as a carer." Female 30-40 years, caring for child with disability and husband with mental illness

"I am a person with a disability who is a carer for my child with a NDIS plan and also a carer for my parent who is eligible for the Aged Care. This takes up a lot of time and energy and I don't have anyone supporting me apart from my husband." Carer aged 45-64, caring for a child 7-14 years.

"Carers should not be marginalised by a system that is designed to support their children with disability- Carers do so much unpaid work for what others attract large funds. We lose opportunity to participate in ordinary life due to systemic and enduring problems with NDIA bureaucracy." Carer aged 45-64, caring for a child 15-18 years.

"NDIS makes assumptions about my capacity to care, without asking". Carer aged 45-64, caring for a child 15-18 years.

Carers Victoria also surveyed a range of carers to gather their views on the current scheme, and opportunities for improvement. These results are summarised overleaf (Box 1).

Key themes

Carers value what the NDIS has provided for those people with disability who are eligible for the Scheme, which has in part provided first-time access to services and supports that had previously been unaffordable or unavailable.

However, there are a range of changes required to address current limitations in the Scheme that negatively impact unpaid carers - amendments which would also result in improved NDIS participant outcomes.

Some of those relate to the **Scheme's architecture** - the overarching design of the NDIS, the complexity of its operating model and the challenges in navigating the interfaces between the NDIS and mainstream services, particularly health and education.

Others relate to **how the Scheme interacts with carers** (or fails to do so) - including factors such as if/how the carer's capacity to assist is determined, a lack of consideration of the support needs of unpaid carers and the failure to ensure provision of assistance that can help sustain carers in their unpaid - but often intensive - support role.

Box 1 – The NDIS Review – what matters to Victorian carers

How is the NDIS working well for Victorian carers?¹

With NDIS it is now possible to use supports and services which are otherwise unaffordable.

With NDIS funding, it is now possible to use supports and services that are essential to helping the person live independent of me.

With NDIS funding, it is now possible to use preferred service providers and get the outcomes needed.

Victorian carers' top 3 problems or concerns with the NDIS

The plan does not include supports or budget to help me to do my caring role.

I cannot access respite for myself.

It is difficult to use the Plan budget to achieve the person's goals because of service issues.

Victorian carers' top 3 impacts of the NDIS

Lack of time for myself

I am not able to work as many hours as I would like or need.

My financial situation is challenging and stressful.

Victorian carers suggestions for enhancing current arrangements

Every plan should include a specific section about my goals as a carer and the supports I need.

Funded respite for carers.

Record details of my care role including health and wellbeing needs alongside participant information.

The system is complex, and often exhausting to navigate – and has not achieved the original intent of relieving excessive stress on informal carers

Over the 10 years since the Scheme was established, Carers Victoria has consistently heard from carers that navigating the NDIS bureaucracy and market is a complex, onerous and frustrating process.

This echoes themes previously put to the Review Panel through a range of submissions and consultations and is also reflected in research such as that by the National Institute of Labour Studies, which showed carers report being overwhelmed by the task of service navigation and long waiting periods to access services.ⁱ

These challenges are compounded for those people who are in care relationships with multiple people and may themselves be both a carer and a care recipient.

The current design of the NDIS has entrenched an artificial division between participant and carer(s), jettisoning one of the Scheme's original goals to "relieve the excessive stress on informal carers."ⁱⁱ

¹ It should be noted that far fewer carers reported NDIS funding enabled access to services for independent living (25%) and using preferred services to achieve the outcomes needed (20%).

Improving the efficiency and user navigation interface of the NDIS would reduce negative impacts on carers, and see more NDIS participants accessing the services they need faster.

Understanding the needs of carers is essential to sustain them in their care relationship, yet few are asked about their needs - and support to sustain them is not provided

Analysis of 2022 National Carer Survey data indicated that while 76% of Victorian respondents reported that they were involved in NDIS planning and decisions about services, far fewer (29%) reported being asked about their needs.

Responses to the Carers Victoria survey to inform this submission also spoke of instances where assumptions were made about their capacity to continue in their role without checking with the carer themselves. Such assumptions have the potential to be detrimental to both the participant and the carer.

Disregarding carers' needs and limiting their opportunities to access respite has significant impacts on their health, workforce participation and opportunities for retirement. Carers commonly report during consultations that NDIS services are unavailable when they cannot provide care, and the Scheme has been a barrier to workforce participation.ⁱⁱⁱ

Carers' access to respite is not provided to them in their own right by the NDIS but rather chanced upon through the 'respite effect' of increased economic and social participation of the participant. As the Productivity Commission found in 2017, "without respite services, the sustainability and success of the Scheme are imperilled."^{iv}

Better support for carers will improve the retention of care relationships, in turn smoothing the journey of NDIS participants towards personal outcomes.

Carers do not feel like their views and experiences are respected or valued - and there are few opportunities for these to influence how the Scheme operates or might be enhanced.

Many carers report that they feel that they are not recognised or respected, with analysis of a survey unpaid carers across Victoria suggesting that less than 16% of respondents felt that government recognised their role and contribution.

The current design and governance arrangements of the NDIS maintain a strong and appropriate role for individuals living with disability, but there is no clear role for carers to contribute through these structures despite their important function.

Better accessing the views and perspectives of carers through design and planning processes will enhance the responsiveness and effectiveness of the NDIS.

The solution – shaping a more sustainable and inclusive Scheme

Within the NDIS, an artificial division between participants and their carers has become entrenched. Carers Victoria is a strong supporter of the central tenets of choice and control, but believes that more often than not, the interests and insights of carers and participants are aligned and/or complementary.

Failing to consider those perspectives, and/or failing to consider the needs of all people in care relationships risks compromising the effectiveness and longer-term sustainability of the Scheme.

The NDIS Review offers an outstanding opportunity to reset the architecture of the Scheme and return it to one of its original intentions of supporting both participants and their carers. Importantly, this offers the potential to contribute to the overall sustainability of the Scheme – and the overall wellbeing of those who support it through the provision of unpaid care.

Simplify assessment and planning processes to reduce the time and resources required by carers to support participation in the Scheme

The Interim Report has identified assessment and planning processes as confusing and stressful. Many carers who speak to Carers Victoria note that while the NDIS participant/s they support would be unable to navigate these without their support, current processes require carers to dedicate significant amounts of time and energy.

In some cases, carers have spoken of the administrative burden associated with participation in the Scheme impacting their own ability to participate in work, study or social activities is compromised. This has the dual effect of impacting poorly on both the carer and participant and threatens further entrenching disadvantage.

This is an area ripe for improvement and streamlining, and we welcome the Inquiry's focus on opportunities to address the current complexities.

Ensure the capacity, needs and intentions of carers are regularly assessed

Carers are often providing a significant level of support alongside funded services, but their needs are not routinely assessed and carers report instances where assumptions are made about their current/future capacity.

Going forward, routinely seeking advice directly from the carer about their current capacity and future intentions will be essential to ensure that the arrangements put in place through the NDIS are sustainable.

The Productivity Commission's 2011 report provides a roadmap for how these arrangements should work: that NDIS planning should be equally informed by conversations and assessments of the participants and carer(s) which "*seek to identify [the carer's] views on the sustainability of arrangements and the ways in which the NDIS should support their role*".

These processes also provide an important opportunity to assess the needs of unpaid carers as individuals, as well as how they pertain to the care relationship.

Ensure that carer needs can access the support they need to sustain them in their role

As the Independent Advisory Council to the NDIS asserts: "Support for families and carers of people with disability is *critical for positive participant outcomes and for the sustainability of the NDIS*" (emphasis added).^v In the 10 years since the Scheme was launched, Commonwealth "funding for support services to assist carers with their own needs has been declining".^{vi}

Unfortunately, there are no established and ongoing national arrangements that consistently provide carers of NDIS participants with that support.² Moreover, the Carer Gateway does not meet carers' ongoing needs and only provides funding for short-term supports.

With unpaid carers reporting significantly poorer physical and mental health, and a substantially higher level of disability reported amongst carers when compared to the general population, a failure to provide this support will likely see more carers need to step away from their caring responsibilities which would place additional pressures on the Scheme.

The Interim Report has identified that what constitutes 'reasonable and necessary' supports is unclear and can be misinterpreted by both those seeking support through the Scheme and the Agency. Some of the supports which meet these criteria include respite, succession planning (including legal and financial advice) and counselling, all of which would significantly benefit many carers supporting participants, and Carers Victoria thus encourages the Review Panel to consider whether amendments to this definition, or an alternative mechanism, might be a suitable way of introducing the concept of support for carers into the Scheme.

Embed a role for carers of participants in governance, design and oversight functions

While many unpaid carers have deep lived experience of interacting with the NDIS, currently there are few opportunities for them to contribute that expertise to enhance the governance, design or oversight of the Scheme. In Carers Victoria's view, this represents a missed opportunity to drive continuous improvement.

Providing a clear and public role for these structures and those associated with Scheme design and review would provide a significant benefit by adding the insights of unpaid carers who often play a central role in advocating for, coordinating and supplementing NDIS supports. Importantly, including carers in such bodies and processes would also be a strong and powerful recognition of the role they play in contributing to the overall aspirations of the Scheme.

Carers Victoria notes that such changes have been made in new Victorian Mental Health and Wellbeing legislation alongside the Health Departments' workforce. Those changes, and recommendations of the Victorian Royal Commission into Mental Health that triggered the reforms, would provide the Review Panel with valuable insights into how this can be achieved in way that respects the importance of both the lived experience of individuals participating in the Scheme and the unpaid carers and others supporting them.

² In its submission to the 2022 Senate Select Committee on Work and Care Inquiry (October 2022), the Department of Social Services and Services Australia has indicated only 4% of carers have registered with the Carer Gateway since its launch, and the current system provides short term support rather than meeting ongoing carer needs.

References

ⁱ National Institute of Labour Studies Flinders University (2015) Evaluation of the NDIS Initial Report, p.34. Accessed 9 August 2023. [National Disability Insurance Scheme | Department of Social Services, Australian Government \(dss.gov.au\)](https://www.dss.gov.au/national-disability-insurance-scheme)

ⁱⁱ Productivity Commission 2011, Disability Care and Support, Report no. 54, Canberra; Volume 2, p. 693.

ⁱⁱⁱ Ibid.

^{iv} Productivity Commission 2017 National Disability Insurance Scheme (NDIS) Costs, Study Report, Canberra, p. 355.

^v Independent Advisory Council to the NDIS (November 2020) Support for families and carers, page, 3; accessed 1 August 2023

^{vi} Ibid, p. 13.