

# CarersACT



## CARERS ACT SUBMISSION TO THE CONSULTATION ON THE DRAFT LIST OF NDIS SUPPORTS

August 2024

## Executive Summary

As the peak body for carers in the ACT, we exist to raise the voices of carers to instigate change. We carry the voices of carers across the spaces they feel unheard to create a community that values and respects the role of a carer. In our role as an advocate, we work to ensure that carers benefit from improved outcomes in health, wellbeing, resilience and financial security, locally and nationally. As the voice of carers in the ACT, we are in a prime position to respond to the recently released Draft List of NDIS Supports (Draft List).

When the National Disability Insurance Scheme (NDIS) fails to provide the necessary supports for participants, the responsibility for this support falls on carers; financially, emotionally, and physically.

In reviewing the proposed Draft List, Carers ACT is disappointed to see that once again, supports that are reasonable and necessary for a carer to maintain their caring role have been overlooked. The importance of supports for carers is not a new argument, it is one that has been made since the NDIS was first being developed and one that we encourage you to read more about in the submissions we lodged during the NDIS Review Part 1 and Part 2.

In any conversation we have with carers about the NDIS their response ultimately always relates back to the very basic and fundamental need to have a break from caring and for systems to take a holistic view of their situation.

Carers ACT truly appreciates the aim of the Draft List is to remove ambiguity by clearly setting out eligible, ineligible and circumstantial supports. However, the NDIS was established with the fundamental principle of providing flexible and personalised support to meet the unique needs of individuals with disabilities. A rigid list such as the one proposed undermines this principle by failing to consider individual circumstances and goes against the very ethos upon which the NDIS was founded.

Similarly, Carers ACT is concerned that the initial two-week consultation period for the draft NDIS List is inadequate and undermines the principles of community consultation. Although the timeframe was slightly extended, many carers, who are already time-poor, remain unaware of the opportunity to contribute, despite our best efforts to disseminate this information.

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## Carers need recognition in the NDIS

***“The NDIS say yes we’ve got stuff for carers... but when it comes to actually receiving it, you can’t actually, practicably access it. The recognition is lip service”. Canberra Carer, 2024***

Despite the numerous mentions within the NDIS Review Final Report of the fundamental role that carers play in the lives of people with disability, the acknowledgement that the NDIS could not function without carers has not translated into any meaningful support or recognition.

### Explicit Carer Supports

Carers contribute \$77.9 billion of unpaid care each year,<sup>2</sup> a figure more than twice the entire NDIS 2021-22 budget<sup>3</sup>. For Australia to continue to enjoy this level of unpaid labour, explicit supports that enable carers to maintain the ability to provide care or build their capacity to care must be included in the NDIS List of supports.

Including carer-specific supports in the NDIS is crucial for addressing the full spectrum of needs within a care relationship. By explicitly integrating the word "carer" into the Draft List, carers can access essential supports that are otherwise unavailable, enabling a more nuanced, targeted, and specialised approach to care.

Excluding carers from the NDIS confines them and the people they care for within rigid boundaries, with overly narrow goalposts that fail to capture the holistic nature of their situation. Carers play a vital role in the well-being of people with disabilities, and recognising their needs within the NDIS framework ensures that the support provided is comprehensive and effective, ultimately benefiting both the carer and the person they support.

The Federal *Carer Recognition Act 2010* (Cth) outlines the principles of recognition and support required by public service agencies, such as the NDIS, to acknowledge the social and economic contributions made by carers. The NDIA should consider this legislation when developing a list of supports. Adequate recognition of carers is an area of national significance, given the current development of a National Carer Strategy that aims to ensure systems like the NDIS are easy for carers access and use. Carers ACT encourages the Review Panel to reflect on the timeliness of this national focus on supporting Australia’s carers and use it as an opportunity to proactively demonstrate recognition and respect for carers in the NDIS.

### Respite

***“Every time I am vulnerable and tell people that I need help. It's oh, well, he goes to school, so you get respite. OK, but that school is sending him home. And they're calling me and jumping up and down the whole time he's at school, so what respite am I actually getting?” Canberra Carer, 2024***

The most commonly raised example of a support that is necessary for a carer to continue providing care to a person with disability is respite. The care provided by carers often surpasses their personal choice and capacity as a result of the care recipient's needs. Carers seldom have the choice about when and for how long they are allowed to take a break, resulting in high reports of psychological distress and low wellbeing.<sup>45</sup> While a person living with a disability may not feel as though they require respite, a break from the demands of the caring role may be essential for the carer’s quality of life and ability to continue caring. At present, however respite is only included in the NDIS where it is a direct goal of the participant. No consideration is given to the goals or needs of the carer, or their capacity to continue caring without respite.

Respite is also unavailable to carers of people who are non-verbal or cognitively unable to ask for or agree to respite care. For carers of people with long term mental ill health, respite is even less likely. The mental health-

specific respite services previously available to carers prior to the implementation of the NDIS have all but ceased<sup>8</sup>.

In addition, because carers are not explicitly included service categories such as in-home respite, many are left in the situation where they are expected to care indefinitely, without any formal rest or reprieve. Explicitly including respite for carers in the Draft List is imperative to ensure carers are able to easily access the respite they require to avoid carer burnout and continue providing care.

## Holistic view

***“You feel like you're constantly asking for something that you're not supposed to be getting almost and trying to justify why it's necessary rather than it being, “how can we help your whole life and the person you care for to come together in such a way that's better for both of you?” - Canberra Carer 2024***

Carers ACT reiterates that we appreciate the need for a tool that removes ambiguity and provides clarity on what can and can't be covered by the NDIS. However, the consequences of a restrictive list that does not take into consideration the whole story of a person's situation will never result in positive outcomes.

A definitive list of what can and can't be covered by the NDIS undermines a holistic understanding of individual needs, which often leads to essential supports being overlooked. For example, a robot vacuum cleaner might be deemed lifestyle or day to day living related and therefore not covered. However, for someone who physically cannot vacuum and cannot have a support worker assist, their carer is left to deal with the task. In such cases, the robot vacuum isn't just a convenience, it's a necessary support that enables the carer to focus on other aspects of care.

Another example is gym memberships, which would fall under 'day to day living' (except in some circumstances). Yet from a more holistic view, attending the gym together might offer the person physical and mental health benefits, while providing the carer with much-needed respite and an opportunity for self-care.

Carers frequently suggest that a more flexible approach, where they can provide a rationale for why a support is reasonable and necessary, would be beneficial, particularly for those who self-manage their plans. Without this flexibility, the responsibility and financial burden of providing these essential supports often fall on carers, who are already financially disadvantaged by their role.

## Conclusion

Carers ACT urges the NDIS Review Panel to reconsider the proposed Draft List with a deeper understanding of the vital role carers play within the disability sector. The current approach, while aiming for clarity and consistency, risks marginalising carers by ignoring their unique needs and the essential supports required for them to sustain their roles. By explicitly including carer-specific supports, such as respite, and instead adopting a more holistic, flexible approach, the NDIS can more effectively uphold its founding principles of personalised and responsive support. Recognising and addressing the needs of carers within the NDIS framework is not only a matter of fairness but also a critical factor in ensuring the long-term viability of the Scheme and the well-being of both carers and the people they support. Carers ACT looks forward to working with the NDIA to create a more inclusive and supportive environment for carers across Australia.

## References

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