



Carers WA



Carers WA Policy Submission

NDIS Rules: New Framework Planning

March 2026

About Carers WA

Carers WA is the peak body representing the needs and interests of carers in Western Australia and is part of a national network of Carers Associations. Carers provide unpaid care and support to family members and friends with disability, mental health challenges, long term health conditions (including a chronic condition or terminal illness), have an alcohol or drug dependency, or who are frail aged. The person they care for may be a parent, partner, sibling, child, relative, friend or neighbour.

Caring is a significant form of unpaid work in the community and is integral to the maintenance of our aged, disability, health, mental health, and palliative care systems.

Some important facts about carers include:

- There are currently 3.04 million unpaid carers in Australia.
- There are more than 320,000 families and friends in a caring role in Western Australia.
- The replacement value of unpaid care, according to a report undertaken by Deloitte, Access Economics, "The economic value of unpaid care in Australia in 2020" is estimated at \$77.9 billion per annum.

Acknowledgement of Country

Carers WA acknowledges the Wadjuk Noongar Nation's lands, water, customs, and culture of which the Carers WA Head Office is located. Carers WA recognises our services reach beyond the Perth (Boorlo) region, and so we also acknowledge the cultural diversity of First Nation Peoples across our state and throughout Australia.



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1.0 Recommendations

1. Carers be recognized, included and supported throughout the process proposed in the NDIS rules: new framework planning.
2. Carers be defined as per the definition under the *Carer Recognition Act 2010* (Cth) and included in all resource language and consultation processes.
3. Consultation resources be provided in a format more accessible for different cohorts, including CALD communities, First Nations peoples, and people with literacy and technology challenges.
4. Future consultations and resource development ensure the inclusion of carers and carer feedback from the very beginning.
5. The proposed new framework planning process ensure that carers' workload to navigate and use the NDIS is reduced.
6. Consideration be given to funding support for navigation or administrative assistance to ease the administrative burden placed on carers.
7. Clarity be provided on:
 - the transition plan for the proposed new framework planning, including what tools will be used. i.e. education sessions from organisations that communities trust.
 - Timeframes between assessment, plan building and plan approval.
8. The use of the word 'impairment' in NDIS processes be reconsidered in consultation with the carer and disability community.
9. Clarity be provided regarding assessors, assessor qualifications, safety checks and clearances, assessor affiliation to the NDIS/NDIA, and the roles and responsibilities of other NDIS delegates in this process. i.e. LACs.
10. The proposed new framework planning process be tested and adapted if required before full system implementation.
11. The proposed new framework planning process have ongoing monitoring, evaluation, and continuous improvement processes, including in response to participant and carer feedback.
12. Opportunities be provided for participants and carers to provide ongoing feedback on the proposed new framework planning process throughout the rollout of the system.
13. Clarity be provided on:
 - how the support needs assessment will take into account the less visible needs of people with neurodiversity and hidden disabilities.
 - how the support needs assessment will recognise, include and support carers of people with disability.
14. Measures be taken to ensure:
 - the new framework planning process is trauma informed.
 - Funding continuation where delays occur.
 - Clarity in roles and responsibilities, including those of the participant and the carer.
 - Clarity in processes such as changing assessors if required.
15. Alternative formats and clearer offline communication options be considered for future resources.

16. Future resources for the proposed new framework planning process be:
 - Inclusive of consultation with the carer and disability community.
 - Include case studies, examples and videos with people with lived experience of disability and caring.
 - Include different formats for resources for the different steps
17. Consideration be made within the proposed new framework planning process for carer capacity and support needs.
18. Changes in a carer's situation or support provided by a carer be incorporated into the plan variations rule to ensure access to emergency or crisis funding in these circumstances.

2.0 Introduction

Carers WA (CWA) appreciates the opportunity to provide feedback to the federal Department of Health, Disability and Ageing, in relation to the public consultation on the NDIS rules: New framework planning.

Carers WA acknowledges the intent and actioning of recommendations and concerns raised during the NDIS Review and other Inquiries, but is deeply concerned at the apparent lack of consideration of carers within the proposed new framework planning process.

Carers WA endorses the United Nation's Convention on the Rights of Persons with Disabilities (CRPD), of which Australia is a signatory, and strongly believes 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. We also acknowledge the 38.6% of carers who also have disability¹ on top of their caring role, an intersectionality which is often missed in disability support service conversations. This submission is made to support both carers of people with disability, and people with disability who are also in a caring role.

For the purposes of this submission, the term 'carer' is defined as per the meaning under the *Carer Recognition Act 2010* (Cth), this being an individual who provides personal care, support and assistance to another individual who needs it due to having disability, a medical condition (including a terminal or chronic illness), mental health challenges, or who is frail and aged. A carer does not include someone who provides care or assistance as part of a contract for services or volunteer work.² A carer may include a friend, family member, neighbour or other contact³. Carers can be aged under 25 (young carers) or be older carers.

This submission and included recommendations are informed through ongoing feedback from WA carers, inclusive of a consultation session with carers examining the individual steps of the proposed new framework planning process.

¹ (Australian Bureau of Statistics, 2022)

² (Commonwealth of Australia, 2010)

³ (Commonwealth of Australia, 2010)

3.0 General Feedback

3.1 Context

'It is very person centered, but it's not carer centered... if you are omitting that from this template or whatever feedback framework, so then how do you expect any support? Everything is focused on the participant, which I can understand, but you cannot ignore the fact that participants can be dependent on a carer or a family member. So I'm really not happy to see that framework. It feels like that we don't exist even though our whole life has changed since we are a carer. The meaning, the purpose of life has changed. We are no more an individual, we are just a carer. So I can't see myself in that framework.' – feedback from a carer

In Australia, there are over three million carers⁴, 38.6% of whom have their own disability⁵, who provide informal care that is valued at \$77.9 billion per annum⁶. In WA, there are more than 320,000 carers, who collectively provide \$6.6 billion dollars of unpaid care per annum. The demand for carers is projected to increase 23% by 2030, but the number of carers available is only projected to increase by 16% over this timeframe. For WA, this represents a shortfall of 22,400 carers at a cost of over \$600 million per annum for replacement care, a shortfall which is exacerbated when carers are not recognised, included and supported in NDIS processes.

Carers play a significant role in supporting the people they care for, including in helping to sustain their independence in the community. Carers advocate, provide personal care and emotional support, attend and organize appointments, and any other task which may be required of them. However, carers' own wellbeing frequently suffers as a result of these responsibilities, an impact which is magnified when a carer has their own disability, health condition or other intersecting experience that places them at a disadvantage. Increased complexity of caring role further adds to this strain⁷.

WA carers have wellbeing levels 20% below that of the average Australian population, a gap which can be reduced and lifted through changes to carer recognition and social factors⁸. Carers also experience higher rates of psychological distress, and poorer health.⁹ An increase in formal recognition of carers can increase carer wellbeing and levels of recognition from family and community, having positive impact on longevity of the caring role and quality of life for both the carer and those they care for.¹⁰

Carers with disability or other health conditions report having significantly lower wellbeing than other carers and the average population; they experience a higher rate of psychological distress; and 68.9% feel socially isolated.¹¹ Over one in three carers from this cohort provide care to two or more people, more than half provide 24/7 care and/or have been caring for more than ten years, and 84.9% live in the same household as the person they care for.¹²

⁴ (Australian Bureau of Statistics, 2022)

⁵ (Australian Bureau of Statistics, 2022)

⁶ (Deloitte Access Economics, 2020)

⁷ (SAGE Design and Advisory, 2025)

⁸ (SAGE Design and Advisory, 2025)

⁹ (Deloitte Access Economics, 2020)

¹⁰ (SAGE Design and Advisory, 2025)

¹¹ (Carers NSW, 2025)

¹² (Carers NSW, 2025)

On average, carers forgo (to age 67) \$175,000 in superannuation and \$392,500 in lifetime earnings. For the most impacted 10% of carers, this increases to a loss of \$444,500 in superannuation and \$940,000 in lifetime earnings¹³. 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 live¹⁴. Nearly one in four carers said they only sometimes (19.7%) or never (4.3%) had access to affordable healthcare¹⁵.

In summary, carers provide significant and crucial support to those they care for, yet are either often excluded from support considerations for those they care for, or it is taken for granted that they will be able to continue to provide care. Where carers are not tangibly recognised, supported and included, this leads to carer stress, burn out and inability to continue their caring role. In the long term, carer wellbeing, mental and physical health, and economic and financial security is adversely impacted. Carers must be considered as part of any planning process within the NDIS, and as part of the proposed NDIS rules: new framework planning.

Carers WA recommends

1. Carers be recognized, included and supported throughout the process proposed in the NDIS rules: new framework planning.
2. Carers be defined as per the definition under the *Carer Recognition Act 2010* (Cth) and included in all resource language and consultation processes.

¹³ (Furnival & Cullen, 2022)

¹⁴ (Carers NSW, 2025)

¹⁵ (Carers NSW, 2025)

4.0 NDIS Rules: new framework planning

'Carers have a really heavy load. What I think should be remembered and kept as a priority is that we don't want more work for us, more stuff. We have to understand what and how the government is going to recognise that carers are already overwhelmed and have enough going on. What tools are going to be used to transition? Education sessions? What support measures are going to be put in place to help us with this change that they've initiated?' – feedback from a carer

Carers WA consulted with carers on its Policy Working Group on the proposed NDIS rules: new framework planning, and also incorporated ongoing carer feedback into the feedback and recommendations below.

Feedback from carers regarding the resources provided for the consultation and to understand the proposed new framework planning included:

- All resources should be available in easy-read format.
- Concerns were also raised on the format of the resources, which carers felt would be inaccessible for people from a culturally and linguistically diverse (CALD) background, First Nations peoples, and people who had challenges with literacy and technology.
- Carers raised that to them the resources were a perfect example that there should have been a carer in the room from the very start of their development.
- Carers liked the case studies which were utilised in the fact sheet for Step 3, and said these should be included throughout the other resources.

Many of the carers consulted found the resources unclear, especially in being able to give an overview of the new framework planning process and how it would impact them and the person they cared for.

Carers WA recommends

3. Consultation resources be provided in a format more accessible for different cohorts, including CALD communities, First Nations peoples, and people with literacy and technology challenges.
4. Future consultations and resource development ensure the inclusion of carers and carer feedback from the very beginning.

4.1 Step 1: Preparing for a support needs assessment

'I'm always a little bit dubious of anytime the NDIS tells me it's going to be better, but I guess last year I got contacted by the NDIS because my son has not yet moved over to the new system and he's had his last three plans just rolled over. And they said they 100%, we won't roll it over again. You have to have all your reports in place, have to have it done by this date. So I spent a lot of time contacting his therapist and getting reports.

Paying a fortune for them [through] Tom's NDIS package. A lot of money was taken from his package to write these reports, which meant he had less speech therapy, less occupational therapy, less money available to do those practical things that actually help him. Then I got a letter in the mail that just said your plan will be rolled over for another 12 months. So, when I rang the NDIS and said you told me I had to have all this stuff organised because it definitely would not be rolled over again. And they just said, yeah, sorry. I think I worked out it was something like \$3400 worth of funding was spent on reports, which I couldn't use, and they're only good for six months.'* – feedback from a carer

**Name changed for confidentiality purposes.*

Carers reported that while they were pleased to hear about a process that may reduce the amount of organising they needed to do and costly reports required, they had concerns about whether the proposed new framework planning would work this way in practice. It was raised that the proposed process should not be something that resulted in more work and stress for carers, and that it should not be yet another level in the system to navigate.

It was raised that the proposed new framework planning did not clearly acknowledge the administrative burden placed on carers, although many carers already manage paperwork, appointments, quotes, invoices and compliance requirements. Carers recommended that consideration be given to funding support for navigation or administrative assistance.

Carers also had concerns regarding limited clarity around timeframes between assessment, plan building and plan approval. Clearer timelines were suggested as being needed to reduce stress and uncertainty for carers and families.

For transition onto the new framework planning, carers recommended increased clarity on what tools would be used, and suggested that education sessions from trusted organisations be included in this transition tool kit. For example, carers said that they would be more likely to go to education sessions on the new process run by carer organisations in each state/territory than to something run by the NDIS/NDIA.

Although understanding that this is out of scope for this consultation, the word 'impairment' was also raised by carers as needing reconsideration. Carers described it as 'awful', that it 'needs changing' and that 'someone should mention something about that'.

Carers WA recommends

5. The proposed new framework planning process ensure that carers' workload to navigate and use the NDIS is reduced.
6. Consideration be given to funding support for navigation or administrative assistance to ease the administrative burden placed on carers.

7. Clarity be provided on:
 - the transition plan for the proposed new framework planning, including what tools will be used. i.e. education sessions from organisations that communities trust.
 - Timeframes between assessment, plan building and plan approval.
8. The use of the word 'impairment' in NDIS processes be reconsidered in consultation with the carer and disability community.

4.2 Step 2: The support needs assessment

Queries were raised by carers as to who would be performing the assessments, what qualifications they would have, what checks would be in place (National and international Police Clearances, Working with Children Check, etc), and whether the assessors would be affiliated with the NDIS or independent. Carers also raised the need for the new framework planning process to be tested, monitored and evaluated, with continuous improvement and system change where required in response to participant and carer feedback.

Carers raised concerns that the nature of the one-off support needs assessment would adversely impact people with neurodiversity and hidden disabilities, as these are not as apparent as physical disabilities and the functional impact of them may differ from day to day. Concerns were raised that if the support needs assessor happened to assess someone with these conditions on a 'good' day, this would result in not receiving the support required. Conversely, if the support needs assessment was done on a 'bad' day, concerns were raised around the length of the assessment and challenge for some people, especially young and neurodivergent people, to get through this assessment.

Concerns were also raised that having to go over information again and again could be quite stressful, and recommended that measures be taken to ensure the process was trauma informed. It was suggested that the support needs assessments have the flexibility to be broken down into a number of shorter sessions if required.

Carers also queried how funding processes would operate under this new system, and whether funding continuation between plans or during time delays could be ensured to make sure participants had the funding needed. Queries were also raised regarding who would be performing which roles under the new framework planning. i.e. who would be coordinating reports and facilitating communication between specialists and NDIA delegates. Carers also asked if they would be able to change the support needs assessor if they needed to. i.e. due to a conflict with the assessor or other reason.

Carers WA recommends

9. Clarity be provided regarding assessors, assessor qualifications, safety checks and clearances, assessor affiliation to the NDIS/NDIA, and the roles and responsibilities of other NDIS delegates in this process. i.e. LACs.
10. The proposed new framework planning process be tested and adapted if required before full system implementation.
11. The proposed new framework planning process have ongoing monitoring, evaluation, and continuous improvement processes, including in response to participant and carer feedback.
12. Opportunities be provided for participants and carers to provide ongoing feedback on the proposed new framework planning process throughout the rollout of the system.

13. Clarity be provided on:

- how the support needs assessment will take into account the less visible needs of people with neurodiversity and hidden disabilities.
- how the support needs assessment will recognise, include and support carers of people with disability.

14. Measures be taken to ensure:

- the new framework planning process is trauma informed.
- Funding continuation where delays occur.
- Clarity in roles and responsibilities, including those of the participant and the carer.
- Clarity in processes such as changing assessors if required.

4.3 Step 3: Building a plan and plan discussion

Carers consulted raised the importance of health literacy and ensuring people who are using the systems can understand the resources made to explain the system. Carers found that the resources developed for the consultation were not easy to find or understand, and did not adequately explain the proposed new framework planning process.

Carers raised that the information within the consultation resources relied heavily on accessing the NDIS website and online resources, which may disadvantage individuals with limited digital literacy, limited internet access (including in regional and remote areas), older carers, or those from culturally and linguistically diverse backgrounds. Carers recommended that alternative formats and clearer offline communication options be considered.

They also raised every additional link or mention of another resource that had to find to try to understand the process, this would result in more work for them as a carer on top of existing carer responsibilities.

However, carers acknowledged that case studies were included in the fact sheet resource for Step 3, and that one of these case studies recognised the impact for carers of not having respite. These were examples which they felt they could apply to themselves and their situations. Carers felt that this resource exhibited understanding of the caring role. Due to these examples, carers found Step 3 and the resources for this step to be the most clear and easiest to understand.

Carers WA recommends

15. Alternative formats and clearer offline communication options be considered for future resources.
16. Future resources for the proposed new framework planning process be:
 - Inclusive of consultation with the carer and disability community.
 - Include case studies, examples and videos with people with lived experience of disability and caring.
 - Include different formats for resources for the different steps

4.4 Step 4: Starting to use a plan

Carers raised concerns that the proposed new framework planning process did not consider the carer's capacity to provide support and their own needs for respite, emotional resilience, training and other assistance to sustain levels of care provided. It was recommended that these considerations be incorporated into the plan variations rule to ensure emergency or crisis funding is also available when support provided by a carer or the carer's situation changes.

Carers WA recommends:

17. Consideration be made within the proposed new framework planning process for carer capacity and support needs.
18. Changes in a carer's situation or support provided by a carer be incorporated into the plan variations rule to ensure access to emergency or crisis funding in these circumstances.

5.0 Conclusion

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

References

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