Carers WA Policy Submission

Feedback to the NDIA

June 2025

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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Contents

1.0 Recommendations

1. Carers and families become a priority area within the NDIS.
2. NDIS and related providers and agencies develop a better understanding of Carer Gateway services, as well as what they can and can't cover.
3. The relationship between carers and NDIS participants be recognized and respected.
4. Within the NDIS, the role and rights of a carer:
    - Become mandatory education for all agencies and service providers within the system.
    - Be recognized and supported in their own needs within and beyond the caring role, to achieve greater economic wellbeing and sustainability, and to participate in family, social and community life.
    - Be treated with dignity and respect.

2.0 Introduction

Carers WA (CWA) appreciates the opportunity to provide feedback to the National Disability Insurance Association as part of the agency’s recent engagement and consultations in WA.

This submission is informed by ongoing feedback from WA carers and staff experience with dealing with carers, including case studies of carer experiences with the NDIA and NDIS, which provide just a sample of what NDIS participants and their carers experience everyday.

3.0 General Feedback

3.1 Carers and Families

Carers WA endorses the United Nations Convention on the Rights of Persons with Disabilities (CRPD), of which Australia is a signatory, and believe that families and carers play an important role in supporting the rights of people with disability in line with the CRPD, where they have been nominated to do so.

Under the *Carer Recognition Act 2010* (Cth), a carer is defined as an individual who provides personal care, support and assistance to another individual who has disability, a medical condition (including a terminal or chronic illness, a mental illness, or who is frail and aged.
Many NDIS participants have chosen to have carers and family members involved in their care, yet this choice is often not respected in the way that carers are treated in their interactions with the NDIS system, nor does it align with The Statement for Australia's Carers (Under the *Carer Recognition Act 2010* (Cth)). Carers are often not recognized, supported, or considered as partners in care. Their contributions are not acknowledged within the system, and their own needs and rights are not considered, even as a way to preserve the longevity of the caring role and caring relationship.

In WA, over half of carers surveyed (55.92%) said they felt unsupported or very unsupported by federal disability services.[1] This stems from gaps in supports for people with disability and carers outside and within the NDIS, as well as a lack of tangible recognition of carers in both these sectors.

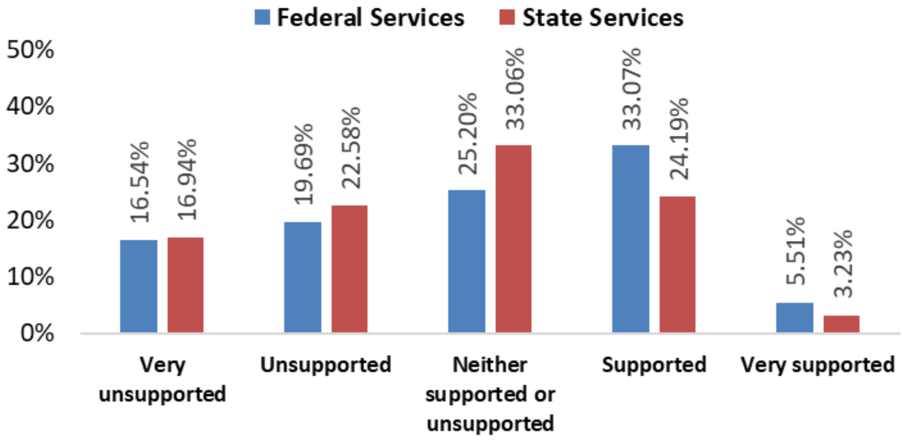

Figure 1 Survey of WA Carers on Disability Services (Carers WA, 2024)

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[1] (Carers WA, 2024)

In Australia, 57.6% of carers provided care for someone accessing disability services, and one in five carers provide care for someone not accessing any formal support services.[2] Across all services, carers were commonly not asked about their needs as a carer, including in mental health services (66.7% of carers), disability services (65.8%) and aged care services (55.1%).[3]

WA has more than 320,000 carers[4], who provide $6.6 billion dollars of unpaid care per year and on average provide 104 hours of care per week[5]. The demand for informal care is spiking and is projected to increase 23% by 2030, however the number of carers available is only projected to increase by 16% over this timeframe[6], leaving a shortfall of 22,400 carers at a cost of over $600 million for replacement care.

Carers play a crucial role in supporting the people they care for, working tirelessly to advocate for their loved ones, provide personal care and emotional support, attend and organize appointments, and any other task which may be required of them by their loved ones. However, where carers are not recognized, supported and connected, this significantly impacts their ability to survive and thrive in their caring role, and substantially impacts the longevity of this role.

WA carers feel significantly unrecognized by government bodies, community, service providers and formal services, which does little to help them feel valued[7]. This lack of acknowledgement impacts on carers' level of wellbeing and on their ability to perform their caring role, have longevity in this role, and thrive outside of their caring role. Increasing levels of formal carer recognition can lift carer wellbeing and positively impact other related areas of their lives, including levels of recognition of their caring role from family, friends and those they care for – which in turn further boosts carer wellbeing[8].

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[2] (Carers NSW, 2025)

[3] (Carers NSW, 2025)

[4] (Government of Western Australia, 2018)

[5] (Deloitte Access Economics, 2020)

[6] (Deloitte Access Economics, 2020)

[7] (SAGE Design and Advisory, 2025)

[8] (SAGE Design and Advisory, 2025)

3.1.1 Carers with a health condition or disability

In addition, what often does not appear to be considered is the additional personal challenges that carers may be juggling on top of their caring roles.

The 2024 National Carer Survey found that nearly half (46.5%) of carers had their own long term health condition or disability, and 40.6% of respondents provided care to someone with physical disability.[9]

Carers who had a long term health condition or disability felt they were significantly less recognised as carers when compared to other carers. They also had lower wellbeing, decreased employment participation, and two-thirds of carers with this experience had one or more experiences of financial stress in the 12 months preceding the survey.[10]

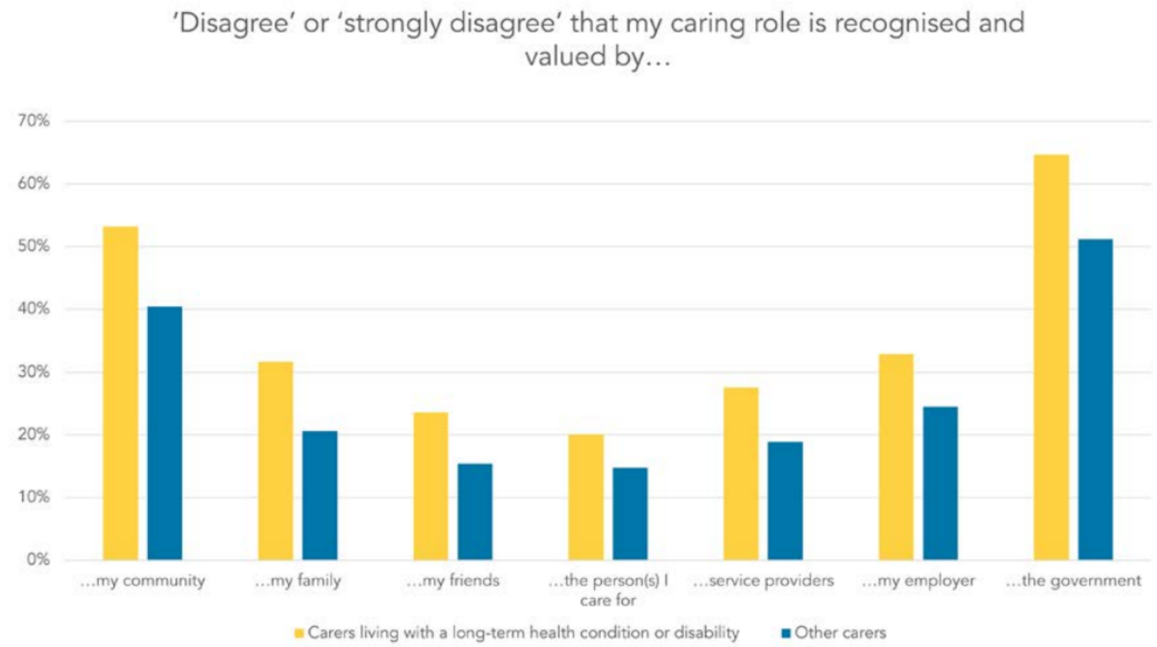

Figure 2 Carer recognition for carers living with a long-term health condition or disability

In addition, carers may also be caring for more than one person, they may be a young carer (carer aged under 25), they may be from a culturally diverse or First Nations background, or identify as LGBQTI+. Carers have many things which may impact on their caring role, and on the person they are providing care for, as well as the carer's ability to continue the caring role.

Consideration of the needs of the carer and their ability to continue their caring role, especially in the absence of requested supports, is reasonable and necessary.

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[9] (Carers NSW, 2025)

[10] (Carers NSW, 2025)

3.2 Ongoing issues experienced by WA Carers

Feedback from carers has indicated the following systemic issues in the disability system:

- System navigation challenges – especially in the midst of ongoing legislative and system changes. Service navigation assistance for participants, potential participants, and their families and carers is needed as a priority.
- Waitlists and availability of services (especially in regional areas) be addressed as a priority. This impacts on access to early intervention and more general supports, which increases the needs of a person with disability over their lifetime, and also increases the impact on their families and carer. In the long term, this increases need for funding and length of time needed on the Scheme.
- Parental responsibility needing to be better defined, with education on what this means. Carers often report this term being used to deny funding or try to shame them into what they should and shouldn't be doing. The demands of a parental role and a parent who is also in a caring are very different, and this needs to be better understood within the system.
- Carer experiences with the NDIS during plan assessment or review involving them feeling judged rather than assessed according to set criteria.
- Lack of clarity around the NDIS Review implementation creates significant uncertainty and stress for carers and those they provide care for. There is a need for an implementation roadmap that covers the five-year implementation period.
- NDIS participants not receiving levels of support as recommended by their specialists. This not only has an impact on the person with disability, but also on their carers, including on their ability to work, study and participate in community. This results in carers needing to stay on government payments, out of the workforce, and with the people they care for as the system is not meeting their needs.
- There is a significant workforce problem within the NDIS system – there is a lack of skilled workers and assessors, as well as issues with workforce retention, which carers have reported has increased in the last twelve months. This is not just a regional issue, and the impact of newer workers coming through all the time is an increase in inconsistent practice, undertrained staff, and incorrect messaging being told to NDIS participants and carers.
    - Carers have also reported receiving random and unclear calls from NDIS planners, and they are then told later that it was a plan review. As a plan review often requires significant preparation, the adhoc nature of these calls results in NDIS participants not having adequate supports in their plans, with carers needing to pick up where the system falls short.

- Further, carers are significantly concerned about the needs assessor roles which are being established. It is not clear how these roles differ from the independent assessor system which was considered several years ago. It is also unclear how the number of needs assessors will cover the amount of NDIS participants needing assessment, or how this assessment will be superior to those done by the participant's specialists, or a true reflection of the person's needs.
- The impact of simply accessing and navigating the NDIS system on carers is significant, leading to increased stress and carer burnout.
- The insurance-based nature of the system assesses the presence of informal supports to reduce the cost of supports to government, yet these informal supports are already working far beyond their capacity, reducing the potential longevity of the caring role. In amongst this, supports are reduced with no consideration given to carer recognition and maintenance of carer wellbeing as a reasonable and necessary component of a standard NDIS package.

3.3 Case Studies

Case Study 1 – Julianne and Alex

Julianne is a carer for her 7 year old son Alex*, who has level 3 autism and a PDA profile. Julianne is a single mother, with no other supports and another young daughter as well, whose mental health and wellbeing has also been significantly impacted by Alex's disability. Her daughter's psychologist has specified that she can no longer be involved in helping care for Alex.*

At Alex's recent plan review for the NDIS, he received significantly reduced funding due to a range of reasons, despite having a substantial amount of evidence to support funding requests. Julianne said that the planner they met with seemed to think that autism was a curable and not a long term condition, and made many comments about things being her parental responsibility.

Julianne outlined that:

- *Respite support was rejected because the planner said she shouldn't want to leave her child with strangers. This was raised as not being the case, as respite services were offered by their support worker. Alex would have been cared for during this time by a familiar support worker.*
- *A step down plan for support work was given, with only 26 weeks of support work hours. Julianne raised that this was not even enough to cover her university study hours. The planner said that best practice was for Alex to be in school. Alex is currently home schooled as the adjustments needed to be made for him to attend a mainstream school would not have been 'reasonable' as outlined in the School Education Act 1999 (WA).*
- *Alex needed supports, without which the long term impact would be significant, not only due to lack of benefit from not having early intervention. She worried that Alex would end up in the justice system due to his behavioral difficulties, and said that many children with his disability were in the foster system due to their level of care needs.*
- *Julianne said she felt like the NDIS planner wasn't giving any choice or control at all, and that Alex's human rights as per the UNCRPD were not being supported. The planner had also said that they could no longer use their current support providers, as Alex's need for supports had increased (despite no evidence of this), and said that Julianne had chosen the wrong providers. Julianne tried to explain that her son needed time to adjust to new support providers. The planner also said that Julianne had wasted and misused funding by going to a carer training course specific to her son's disability, and told her off for this (despite there being a line item for this training).*
- *Alex's funding ended up being cut in half, with many requested supports being refused. Julianne said since this, Alex's capacity had diminished significantly, and his support ratio need had increased to 2:1.*

Julianne currently cannot work due to Alex's care needs. She estimated that a job she is currently qualified for would have paid $45 per hour ($90,000 per year). This would give the government $22,000 in tax per year. Julianne currently receives $30,000 per year in carer concession payments from Centrelink. She estimated that this was currently a $50,000 per year financial detriment to the government due to not providing her son the support needed for her to reenter the workforce. Julianne also raised that once she finished her studies, her estimated income would be $200,000, presenting a much larger financial loss to government due to her not being able to work due to caring responsibilities.

**Case studies are deidentified for confidentiality.*

Case Study 2 – Mary and Tony

Mary's son Tony* has complex care needs and requires 24-hour support in his own home. There was a breakdown in communication between the support workers and the coordinator, and Tony and the coordinator. This resulted in the support workers going to Mary to intervene and the coordinator not going to Tony's house to monitor the workers. Due to this lack of oversight, the quality of care, support and hygiene in the house declined significantly. There was also not a clear and consistent roster of workers, which was highly stressful for Tony, and no clear person for Mary to contact or know who was on duty. In addition, support workers would leave and not be replaced until there were only four out of the original ten workers still working. This resulted in Mary having to do 17 (24 hour) shifts at her son's house over a three-month period.*

Mary filed several formal complaints over a six-month period to the service provider's senior management and the NDIS Quality and Safeguards Commission, with no improvements seen in the service over this time. The service provider then gave 30 days' notice of their intent to cease service.

Mary worked with Tony's support coordinator, but had great difficulty in trying to find a new service provider in this time frame which had the capacity to manage a person with complex care needs of disability, mental health and health conditions. They approached seven different providers, all of which had an intake wait time ranging from two to four weeks. Tony's NDIS plan also underwent a scheduled review during this time, meaning he no longer met the criteria for Independent Living Options (ILO) funding and instead needed Supported Independent Living (SIL) funding. There was also an accompanying long wait for his SIL plan to be approved, meaning Mary had to share an outdated plan with potential providers even though Tony no longer met the criteria in the plan.

Nearly at the end of the 30-day notice period given, while a suitable service provider was identified, their intake would take 12 weeks to transition support. Further, as Tony has significant challenging behaviour and history of critical issues, the new provider wanted to wait until an updated behaviour support plan was in place. While Mary found the new provider to be very thorough and understood the length of time required to get support staff in place and properly trained to support Tony, the old service provider was adamant that they would not continue past the date given for ceasing services. This would mean that Mary would have to go back to providing Tony with 24-hour support for the twelve weeks, a prospect which was a huge stressor in her life and would have significant impact on her ability to work.

After going back and forth to the NDIS general number and NDIS Quality and Safeguards Commission several times for advice and support, Mary engaged advocates for herself and Tony. The result of the long-drawn out dispute was that the original service provider was found to have a duty of care to continue to provide Tony with support until the behaviour support plan was completed and support workers from the new service provider trained to support Tony. As a result over the changeover time the original service provider also improved communication regarding rostering, and stopped being reliant on Mary as a fall-back unpaid support worker.

**Case studies are deidentified for confidentiality.*

Case Study 3 – Susan and Sean

Susan is a carer for her son Sean*, who has very severe obstructive sleep apnea and a complex heart and spine condition. Susan had a prolonged and difficult experience which she termed 'CPAP hell' in getting an appropriate replacement funded for Sean's Continuous Positive Air Pressure (CPAP) machine after it was damaged.*

Sean requires a CPAP machine to support his sleep apnea overnight, but due to a lack of maintenance of the machine by his support workers and the workers not having the machine packed adequately while it was being transported, the machine was damaged beyond repair. This was following some previous issues with the provider not assisting with hygiene of the machine and timely replacement of consumables.

Sean had gotten this CPAP machine when he was assessed by a hospital sleep specialist, where he was diagnosed with severe sleep apnea and provided with a machine specially calibrated to his needs and funded through the former WA Disability Services Commission. Sean has funding through the NDIS for CPAP maintenance or consumables related to the machine. As Sean had NDIS funding, the state health department would not fund another machine.

When Susan requested that some of Sean's NDIS CPAP repair and maintenance funding be used to purchase a replacement CPAP machine, the NDIA directed her to get an OT assessment. Susan was not able to find an OT with the skills needed for a CPAP assessment, and appealed this requirement, on the basis that a specialist sleep clinic had already assessed Sean. To back this up, Susan obtained a diagnostic report from the original hospital sleep clinic lab technician and a quote with the recommended CPAP machine, equipment and cleaning consumables. The urgency for an appropriately calibrated machine was further increased when, despite being able to use temporary CPAP machines through a loan machine and rental during this process, Sean's support worker had to wake him up when he had cyanosis.

The pharmacy through which the rental CPAP machine was provided then was not able to claim for the cost of the rental machine, which Susan urgently contacted the NDIS Planner about. The NDIS Planner then worked with Susan to identify the most straightforward way to get a CPAP for Sean using his NDIS funding. Some funding was identified to be repurposed for the CPAP machine, for which a plan review was required, as well as making the funding Plan Managed. This meant a Plan Manager could pay for the item from Sean's plan and Susan could then purchase the CPAP from any supplier, whether they were registered as a NDIS provider or not. Susan also got a letter from Sean's cardiologist to further demonstrate the need for the new CPAP machine.

While this method was successful in getting the pharmacy paid for a new CPAP machine, the plan review process then took some time to be resolved, during which there was not funding to pay Sean's plan manager. The revised plan which was sent through was also uncorrected and not resolved of several items, including the CPAP machine funding, which Susan had to further follow up to get corrected.

**Case studies are deidentified for confidentiality.*

Case Study 4: Rita and David

Rita is a carer for her son David* and has self-managed his NDIS funding for David since he first started receiving it in 2020. She describes her experiences prior to, during and after going through the NDIS application process.*

Prior to receiving NDIS funding, David had been receiving limited support through an agency, amounting to a few hours of support per week. The agency would send whoever was available to provide David with community support, which changed constantly. The support workers would also sometimes come late, not at all and one time they even came 24 hours early. Communication within and with the agency was not great and it was not a nice experience for Rita or David.

As the NDIS was new to WA and not in all areas, it took a while for it to become available for David. Once it was available, David's social worker assisted with his application for the NDIS. In the build up to getting the Planning Meeting, Rita described how nerve wracking it was for her, as a lot was riding on getting the funding. She felt an overwhelming sense of responsibility, couldn't sleep well for weeks and said it affected her mental health as she could not think of anything else. It was not an experience she said would ever like to go through again. Rita also found it very challenging to try to explain to someone she had never met the details of someone's life with a mental illness, and how this affected their day-to-day life – particularly when David would often just say he was fine.

Due to the COVID-19 pandemic, the planning meeting was over the phone, during which Rita was supported by a representative from 360 Health + Community. The representative, despite being pregnant and about to go on maternity leave, came to Rita's home to support her and spoke to the NDIS planner throughout the meeting. Rita felt very appreciative to have had the support person with her at the meeting. She also said she wondered how people cope without this support and if people miss out on funding because they cannot articulate their needs.

Rita found the Local Area Coordinator (LAC) to be very nice, patient and understanding. However, there were some questions she was not sure how to answer, including how she (as her son's nominee) would like the plan to be managed. Rita ended up answering NDIA managed as it seemed to be the safest option. Following the meeting, Rita wanted more information on this and researched it further, including through online Facebook forums, until she felt confident to try to self-manage the plan.

David received a good level of NDIS funding, but the LAC which Rita had met with moved on from the role. Rita found this to be a shame as the LAC had done a good job, she had built up a relationship with him and he would always answer her questions. The new LAC sent Rita an email telling her who they were, then she did not hear from them again until David's plan was up for renewal eight months later. David's NDIS plan was renewed with the same level of funding, with only limited input required from the LAC. Rita described how relieved she was when the plan was renewed, and how nerve-wracking renewal time was, with no certainty on if funding was going to be cut or not.

Rita has now been self-managing her son's plan for more than two years, and says David is getting good community and home support. She described how as a result of her research and talking to others she has learnt that not all LACs are knowledgeable about the NDIS, with a lot of incorrect information being provided by LACs as a result. Rita said she has found for complex questions, it is best to phone NDIS direct, but found it quite stressful trying to get correct answers while caring for a loved one also.

**Case studies are deidentified for confidentiality.*

4.0 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.

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