



Carers WA



Carers WA Policy Submission
Department of Social Services - Consultation
on draft lists of NDIS supports
August 2024

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 2.65 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 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. The period of consultation on the draft lists of NDIS Supports be further extended to allow proper consideration by those who are impacted.
2. That future consultations are provided with an adequate time period for proper consideration by relevant stakeholders.
3. The addition of a bespoke NDIS support inclusion section on 'Respite', to include any supports which are required to support the NDIS participant, to give the carer the opportunity to take time out from their caring role, including:
 - In-home respite support
 - Respite support out of the home
 - Ensuring local, available and affordable respite support is available for any NDIS participant and their carer, who has need of it.
 - Respite for children, including out-of-school hours care, vacation care, and other childcare fees where the child is:
 - Not able to access standard childcare due to their disability;
 - Has an increased cost of childcare due to their disability; and/or
 - A NDIS participant who is not able to access standard childcare locally due to other variables. i.e. regional or remote areas; etc.
4. The establishment of mapping of respite care as a priority for all levels of government, and reflect the substantial need for increased respite availability and carer retreats, especially in regional and remote areas.
5. The following amendments be made to the draft list of included NDIS supports:
 - **Exercise Physiology & Personal Well-being Activities**
 - **Description:** Physical wellbeing activities to promote and encourage physical well-being, including exercise, for NDIS participants and/or their carer/s. This is inclusive of any supports NDIS participants may need while the carer is accessing physical wellbeing activities.
 - **Group and Centre Based Activities**
 - **Description:** Assistance for NDIS participants and/or their carer/s to access and participate in community, social and recreational activities provided in a group setting, either in the community or in a centre. This is inclusive of any supports NDIS participants may need while the carer is accessing these activities.

6. Education and awareness initiatives for GPs, child health nurses, childcare workers and primary school teachers on carer awareness and the identification of health conditions such as neurodiversity to improve early intervention impact. This should also include awareness of young carers, and strengthening referral pathways from health practitioners, childcares and schools to carer supports.
7. Mental health and wellbeing supports for carers of NDIS participants with neurodiversity.
8. Inclusion of a section within the draft NDIS funded supports list on neurodiversity, including supports for carers of NDIS participants with neurodiversity.
9. The inclusion of funding for mental health support for people with disabilities within the NDIS.
10. Extending funding for mental health support for carers of NDIS participants as a NDIS funded mental health support for carers, due to the significant impact caring has on carers' mental health.
11. Increasing the amount of sessions available to all carers on a Mental Health Treatment Plan to twenty sessions per annum, with no fee for a GP appointment to obtain this plan.
12. The list of exclusions contain a disclaimer stating that:
 - Exclusions can be overridden if a participant has a need for the support as a result of their disability, with evidence from an allied health professional.

2.0 Introduction

Carers WA (CAWA) appreciates the opportunity to provide feedback to the Department of Social Services in response to its consultation on draft lists of NDIS supports as part of the *National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024 (Cth)* (the Bill).

CAWA endorses the United Nations Convention on the Rights of Persons with Disabilities (CRPD), of which Australia is a signatory, and believe that families and informal 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.

The proposed legislative changes and the prescriptive nature of the draft lists of NDIS supports, effectively disempower people with disability, and remove the choice and control which the NDIS espouses to provide. Further, the narrative around the NDIS and the supports it provides has shifted significantly, from a focus on investment in supporting people with disability now to reduce future cost; to a concentration on the current cost of the scheme.

For the purposes of this submission, the term ‘carer’ is defined as per the meaning under the *Carer Recognition Act 2010 (Cth)*, this being that a carer is 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. An individual is not a carer if the care, support or assistance provided is under a contract or services or for provision of services, is in the course of voluntary work for a charitable, welfare or community organisation, or is provided as part of an education or training course.¹

¹ (Commonwealth of Australia, 2010)

3.0 General Feedback

3.1 Duration of consultation

'Every carer I know needs support, primarily financial, to enable them to get by day to day. Recognition is not going to allow carers to fund their own health needs, pay their bills, take a break, or retire and age with financial or housing security. I feel like a lot of money is being wasted on token reviews that make no difference to the lives of carers.' – response from a carer

While CAWA appreciates the intent of providing and consulting on additional detail prior to the Bill being passed by Parliament, the duration of the consultation (three weeks) on this detail is insufficient to allow proper consideration by everyone who is impacted.

Under Recommendation 25, Action 25.2 of the NDIS Review Final Report, the Department of Social Services is recommended to 'undertake **deep** public consultation and engagement on proposed package of legislative reforms'. This consultation 'should include people with disability, families, carers, Disability Representative Organisations, providers and workers to understand and address potential concerns or unintended consequences of legislative reforms.' Three weeks of consultation is not deep consultation, and is not a sufficient length of time to engage with all these stakeholders.

Carers WA recommends:

1. The period of consultation on the draft lists of NDIS Supports be further extended to allow proper consideration by those who are impacted.
2. That future consultations are provided with an adequate time period for proper consideration by relevant stakeholders.

3.2 Inclusion of carers

'I am a carer - my hope is that governments, organisations and businesses (and the community in general) understand, respect and support my role as an unpaid carer so I can be the best I can for those I care for.'
– response from a carer

Carers play a significant role in supporting many people with disability, often at a great personal cost and detriment to their own wellbeing, particularly when they are not themselves adequately supported, or recognised for their contribution.

This is of particular importance for carers who provide care to one or more people with higher care needs or for an extended period of time, for which their caring roles comes at a significant personal cost. For carers who are in their caring role for a prolonged period, the most impacted 10% will lose at least \$940,000 in lifetime income and \$444,500 in retirement savings² due to having to give up employment to care for others. The 2022 Carer Wellbeing Survey also revealed that carers who had a higher care load (46.3%) undertook less work than they wanted to, had poorer wellbeing than other carers, and were amongst the least likely groups to have accessed support from family and friends in the last 12 months³.

Overall, carers have significantly higher rates of psychological distress than the average Australian. Over half of carers have poor wellbeing, compared to 25.4% of adult Australians. Only 17.1% of carers report having good health, compared to 47.9% for the average Australian⁴. Financial wellbeing is also impacted, with an average reduction of \$175,000 in superannuation and \$392,500 in lifetime earnings for primary carers by age 67. On average, for every year someone is a primary carer there will be a reduction of \$17,700 in superannuation and \$39,600 in lifetime earnings that they would have made if not in a caring role⁵.

Further, the value of this care has been valued by Deloitte Access Economics at \$77.9 billion per year⁶. However, despite this value, carers continue to face a lack of recognition, inclusion and support in key services such as the National Disability Insurance Scheme. This needs to be addressed within the draft lists of NDIS supports.

² (Furnival & Cullen, 2022)

³ (Schirmer, Mylek, & Miranti, 2022)

⁴ (Schirmer, Mylek, & Miranti, 2022)

⁵ (Furnival & Cullen, 2022)

⁶ (Deloitte Access Economics, 2020)

There is a prevailing over-reliance on carers within the NDIA and NDIS, whether the NDIS participant is living in the same home as their carer, or the NDIS participant is largely independent and living in their own home. Despite this, carers report that the NDIS does not provide an allocation of funding for them to take a break, to better enable carers to support the person they care for (which should be above and beyond Carer Gateway funding to be reflective of the higher amount of care required of carers of NDIS participants). This reliance on informal supports then results in carers becoming burnt out and no longer being able to continue in their caring role, which has adverse impact on people with disability.

As a significant and invaluable source of support for many people with disability, the needs of carers must also be considered and accounted for within the draft list of NDIS supports and within core NDIS supports, to ensure carers are able to continue and thrive in their caring role in helping people with disability to maintain their independence, choice, and social and community connections.

3.2.1 Return on investment for supporting carers

The long-term narrative around the NDIS, has been that investment in supports for people with disability now, can reduce longer term costs. Although this focus has shifted to a concentration on the current cost of the scheme, this narrative is one which is also true of maintaining and investing in carer wellbeing.

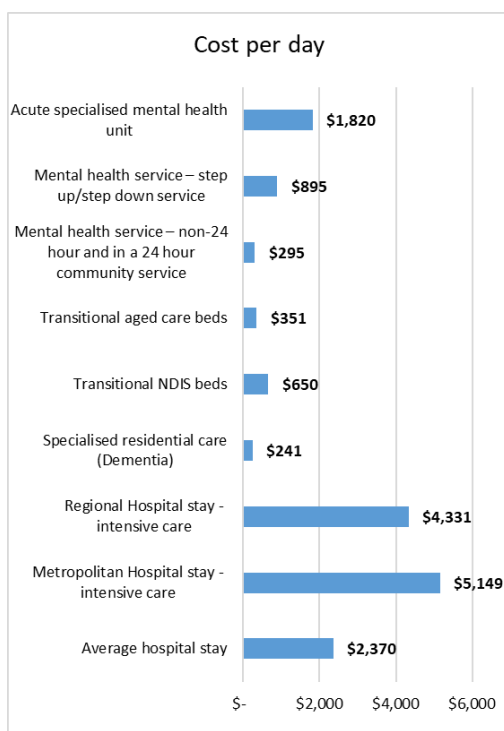


Figure 1 Indicative costs of alternate care arrangements (Office of the Auditor General Western Australia, 2022), (Hicks, et al., 2019), (Gnanamanickam, et al., 2018).

While the demand for carers in Australia is projected to increase 23% by 2030, the number of carers is only expected to increase by 16% over this timeframe. The average value to replace the informal care undertaken by one carer is \$27,821 in wages per year (2020 figures). Holding population levels steady, this represents a total shortfall in WA of 22,400 carers by 2030, with an annual replacement cost of \$623 million for waged workers. This does not account for the cost of other alternate care arrangements for the person receiving care.

As demonstrated in Figure 1, the indicative costs of alternate care arrangements for a person who does not have an informal carer, can be high. When considered on an annual basis, the value of carers becomes even more clear, especially in the case of a long stay patient. Recently, the WA Office of the Auditor General estimated 486 patients waiting for NDIS or aged care services had spent about 40,000 days extra in hospital over a 13-month period, with the cost of care for this being approximately \$71.8 million.

Given the cost of alternate care arrangements, the value of carers and the impending shortfall of carers – it makes economic sense to take better care of Australia’s carers.

3.3 Do you think the draft list of NDIS Supports covers the kinds of disability supports you think should be included? If not, what changes would you suggest?

‘Recognition is better than it has been historically. Enshrining in legislation is a good start, but I feel we have disappeared off the radar with the advent of the NDIS, which can be quite a burden on carers’ already significant responsibilities.’ – response from a carer

While the draft list of NDIS supports covers many inclusions which will be beneficial for NDIS participants, it fails to include supports which are vital to enabling carers of NDIS participants to continue in their caring roles. This includes supports which enable carers to take a break, maintain their mental and physical wellbeing, and be tangibly recognised in their caring role.

3.3.1 Respite

A much-needed clarification and inclusion as a NDIS support, is the inclusion of Respite as a stand-alone section on the draft ‘supports that are ‘NDIS supports’ list’. This section would include any supports which are required to support the NDIS participant, to give the carer the opportunity to take time out from their caring role. This should be available as a core support where required for NDIS participants and their carers (as opposed to a foundational support).

Although ‘short term accommodation and respite’ is mentioned briefly as an inclusion within the ‘Assistance with daily life tasks in a group or shared living environment’, carers often report difficulties with short term accommodation and respite being included in an NDIS participant’s plan. The economic viability of providing short-term accommodation is also often not feasible due to limited availability and high staffing costs. To adequately ensure carers of NDIS participants are supported, and that NDIS participants who have need of a carer are supported in the carer’s absence, respite is a required and important separate NDIS support.

Further, to have a carer fund respite for the person they care for is a significant and often impossible expense to cover, especially for a carer who is surviving only on a carer concession payment. In Western Australia, of the carers who are in receipt of a carer payment, 57% are under the poverty line.⁷ The most common indicators of financial stress experienced by carers include not being able to raise \$2,000 in a week if needed (34.4%) and spending more than they received in a month (33.7%).⁸

⁷ (SAGE Design & Advisory, 2023)

⁸ (Carers NSW, 2023)



Figure 2 Carer experiences of financial stress (Carers NSW, 2023)

Even for a carer who is able to work full-time, the cost of respite can be exhaustive – as demonstrated in the case study below.

Case Study 1:

‘Carol is a carer from the Wheatbelt region in WA who provides care for her grandmother Kate*. Carol works full time, but said she would not be able to cover the cost of respite for even two weeks for Kate, if she was to need it. Carol said that cottage respite in the region currently costs \$83.96 per day, and residential respite ranged from \$61.96 per day and can be higher in metropolitan areas. Carol also said that Aged Care facilities that offer overnight respite services need to determine the ability of a client or their carer to pay for services before continuing with and confirming any respite bookings. There are currently no payment plan options available through the aged care facilities to cover the Daily Service Fees and additional service charges, if relevant. These charges must be covered by either the person being cared for, carer or through other funding sources.*

**Names changed for confidentiality purposes.*

Recommendation 25 of the Final Report of the Select Committee on Autism, recommends mapping be undertaken of respite and support services for parents and work with government and non-government providers to address identified gaps in support. This recommendation was supported in principle by the Federal Government, and referred to state and territory governments for consideration. Reference was also made to carer ability to access respite through the Carer Gateway and NDIS participant packages.⁹ However, access to respite remains severely limited due to limited availability and high demand. This is particularly pronounced in regional areas of WA.

Informal carers experience increased and heightened levels of social isolation, loneliness, psychological distress, as well as ill health and low wellbeing. The impacts of caring have

⁹ (Senate Select Committee on Autism, 2022)

increased during and in the aftermath of the COVID-19 pandemic, particularly in remote and regional areas, as well as for people who provide care for or are part of high-risk groups – such as carers of autistic people¹⁰. Access to respite for an informal carer can help carers to have a healthy level of wellbeing¹¹, and better maintain and thrive in their caring role. Despite this, many barriers exist which hinder carers being able to access an appropriate level of respite services. For different types of support, the majority of carers report having poor access to in-home overnight respite care (80.6%); overnight respite care out of home (73.9%); day respite care out of home (65.7%); and in-home day respite care (61.8%).¹².

In regional WA, access to respite and the ability for carers to take a break is even more constrained, leading to increased isolation, burn out and low wellbeing for carers. Indeed, 24% of WA carers are in crisis, with many of these being in regional areas.¹³

3.3.1.1 Respite for children with disability

‘Due to my autistic son’s complex nervous system disability and manifestation of this behaviourally, he has been terminated from two childcare centres. I am trying to maintain employment and juggle his care and this is significantly challenging as the NDIS do not recognise this as a point for support, claiming childcare is a parental responsibility. Though there are no suitable options for him to attend childcare.’
– feedback from a carer

Carers have reported that it is easier to access Carer Gateway services to support them in their caring role, while caring for children with disability, than accessing any NDIS support. At times such as school holidays where their children cannot access mainstream supports, carers are having to access respite through the Carer Gateway in order to maintain their employment. Specific cases include:

- Carer Gateway funding for a family to access in-home respite for their two young children with disability, due to a lack of appropriate options around childcare or babysitting services;
- Carer Gateway funding for a carer in a regional area to support with in-home respite for her child with a disability. Their NDIS funding was already exhausted, there were no accessible or inclusive school holiday program providers in town and the carer had to work through school holidays.

In addition, carers of children with autism report having limited options when accessing care or respite for their children, and often experience not being able to access such services. This results in carers not being able to return to work until their child enters the public school system, if they are able to return to work at all on top of their caring role. There is a need for increased options for appropriate care supports for children, including school holiday programs, which are more accessible and inclusive for children with complex needs, including children with autism and disability.

¹⁰ (Schirmer, Mylek, & Miranti, 2022)

¹¹ (Schirmer, Mylek, & Miranti, 2022)

¹² (Schirmer, Mylek, & Miranti, 2022)

¹³ (SAGE Design & Advisory, 2023)

3.3.1.2 Regional perspectives on respite

Carers WA has conducted extensive consultation in regional areas of WA over the past two years, with all regions consulted reporting issues with access to respite and the need for carer retreats.

The Kimberley region reported a severe lack of access to all forms of respite, with one-third of service providers consulted raising concerns about access to respite or opportunities for carers to have a break. Carers in remote communities were particularly flagged as having no access to respite.¹⁴

In the Great Southern region, lack of respite and carer retreats was identified as the most significant issue for carers in this region. Fifty percent of local service providers consulted identified respite related needs for carers, again for all forms of respite. The impact of this limited availability was reported to be lengthy hospital admissions, as well as some hospital discharges which were described as inappropriate, further resulting in readmission. The main underlying contributing factors for this issue were availability and affordability of respite, as well as workforce issues.¹⁵

In the Goldfields region, the ability of carers to access respite was found to be particularly dire. This was compounded by some Kalgoorlie hospital services being discontinued due to funding, which had a domino effect on carers in the region. The community spoke of the existing aged care providers now either not having any respite beds or not taking any more bookings for respite beds due to extensive waitlists. Existing providers also did not have any high-care respite beds. For other forms of respite, extensive waitlists were reported, resulting in there not being any available respite beds or in-home respite in Kalgoorlie.¹⁶

Respite access in the Esperance region was identified as being limited. Carers described it as frustrating, leading to feelings of burnout and dissatisfaction with their caring role, as well as needing to use the hospital regularly as an emergency respite facility. Nearly one-third of service providers consulted in Esperance identified respite as a significant area of need for carers in the region, whether it be for just an hour a week, in-home respite or residential respite. A need was identified for all forms of respite, as well as accompanying accommodation for staff, due to severe housing shortages in the region.

¹⁴ (Carers WA, 2023)

¹⁵ (Carers WA, 2023)

¹⁶ (Carers WA, 2023)

Carers WA recommends:

3. The addition of a bespoke NDIS support inclusion section on 'Respite', to include any supports which are required to support the NDIS participant, to give the carer the opportunity to take time out from their caring role, including:
 - In-home respite support
 - Respite support out of the home
 - Ensuring local, available and affordable respite support is available for any NDIS participant and their carer, who has need of it.
 - Respite for children, including out-of-school hours care, vacation care, and other childcare fees where the child is:
 - Not able to access standard childcare due to their disability;
 - Has an increased cost of childcare due to their disability; and/or
 - A NDIS participant who is not able to access standard childcare locally due to other variables. i.e. regional or remote areas; etc.
4. The establishment of mapping of respite care as a priority for all levels of government, and reflect the substantial need for increased respite availability and carer retreats, especially in regional and remote areas.

3.3.2 Carer mental and physical wellbeing

'Acknowledgement of the toll both mentally & physically caring takes on Carers. Awareness that carers can and do often care for more than one person. I am caring for 5 family members, Centrelink only recognises caring for 2 adults.' – response from a carer

'Too many people find themselves in the role of a full time 24/7 carer at great detriment to themselves. The emotional, social and financial impacts and burden may be acknowledged but it seems to be mostly in the form of "I don't know how you do it". Resources offered via government seem too difficult to access and meet the needs of so few.' – response from a carer

Caring has a significant impact on carers' mental and physical wellbeing, especially for carers who are providing higher amounts of care and/or caring for more than one person.

Carers WA supports the 'Development of Daily Care and Life Skills' section of the draft inclusion list, where training and development skills undertaken by a participant **or their carer** are included as a NDIS funded support, to increase their ability to live as autonomously as possible. However, other sections of the draft inclusion list would also benefit from extending the support to the carer of a NDIS participant as well, to assist in maintaining the carer's health and wellbeing, and ability to continue in their caring role.

Carers WA recommends:

5. The following amendments be made to the draft list of included NDIS supports:
 - **Exercise Physiology & Personal Well-being Activities**
 - **Description:** Physical wellbeing activities to promote and encourage physical well-being, including exercise, for NDIS participants and/or their carer/s. This is inclusive of any supports NDIS participants may need while the carer is accessing physical wellbeing activities.
 - **Group and Centre Based Activities**
 - **Description:** Assistance for NDIS participants and/or their carer/s to access and participate in community, social and recreational activities provided in a group setting, either in the community or in a centre. This is inclusive of any supports NDIS participants may need while the carer is accessing these activities.

3.3.3 Clearly defined supports for NDIS participants with neurodiversity and their carers

‘Not even my extended family understand how hard it is, so how can anyone else in the wider community get it. I have some friends who are in similar situations, and they are my support, we tend to lean on each other. But there is no awareness of the toll it takes on career, marriage, and divorce, being alienated, feeling blamed for kids’ behaviour when they don’t understand autism. I would love to see more awareness of asking if a carer is ok and acknowledging what they do. The general population might assist more if they knew how hard it can be. Thanks for giving us this opportunity to speak up.’

– feedback from a carer.

Carers report a need for support for carers of people with neurodiversity, as well as increased clarity on funded supports for neurodiverse NDIS participants.

Carers WA recommends:

6. Education and awareness initiatives for GPs, child health nurses, childcare workers and primary school teachers on carer awareness and the identification of health conditions such as neurodiversity to improve early intervention impact. This should also include awareness of young carers, and strengthening referral pathways from health practitioners, childcares and schools to carer supports.
7. Mental health and wellbeing supports for carers of NDIS participants with neurodiversity.
8. Inclusion of a section within the draft NDIS funded supports list on neurodiversity, including supports for carers of NDIS participants with neurodiversity.

3.4 Are there goods or services on the draft exclusion list that you think shouldn't be there? If yes, please list in order of importance.

3.4.1 Mainstream - Mental Health

Carers WA supports the inclusion of ongoing psychosocial recovery supports within the draft list of NDIS supports, but is concerned regarding the exclusion of all other mainstream mental health supports from the funded NDIS supports.

Carers have raised concerns about the removal of mental health treatments, the lack of understanding of mental health by the NDIS, and the impact on individuals with severe mental illness and their support systems.

Recommendation 7 of the NDIS Review Final Report focuses on the introduction of a new approach to NDIS supports for psychosocial disability, focused on personal recovery, and the development of mental health reforms to better support people with severe mental illness. However, given the transitional nature of the draft list of NDIS supports, no government response presently being available to the NDIS Review Final Report, and the five year implementation timeframe within the Final Report – it is concerning that the draft list of funded NDIS supports is excluding most mental health supports when reform is likely to take a significant amount of time.

Carers WA recommends:

9. The inclusion of funding for mental health support for people with disabilities within the NDIS.
10. Extending funding for mental health support for carers of NDIS participants as a NDIS funded mental health support for carers, due to the significant impact caring has on carers' mental health.
11. Increasing the amount of sessions available to all carers on a Mental Health Treatment Plan to twenty sessions per annum, with no fee for a GP appointment to obtain this plan.

3.5 Do you have any further feedback or concerns with the draft NDIS support lists?

3.5.1 Inconsistencies in practice

The discussion paper states that the purpose of the draft lists is to provide clarity for relevant stakeholders when selecting supports, but also outlines that the overarching test remains whether 'a person has a need for the support as a result of their disability and whether the support is most appropriately funded by the NDIS'.

Certain aspects of the draft lists will result in reduced clarity in practice due to disparity between the inclusions and exclusions within the list, and this overarching test. In its present form, the draft list contains exclusions which people will have a need for as a result of their disability, and inclusions which are contradicted or not made clear within the exclusions.

As such, Carers WA recommends:

12. The list of exclusions contain a disclaimer stating that:
 - Exclusions can be overridden if a participant has a need for the support as a result of their disability, with evidence from an allied health professional.

4.0 Conclusion

Should the Department require any further information 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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