



**Submission to the  
Parliament of Australia  
Joint Standing Committee on the  
National Disability Insurance Scheme**

**Inquiry into the NDIS participant experience in rural,  
regional and remote Australia**

**February 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 ill health, 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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## Summary of Recommendations

1. Carer identification, recognition, support and referral be a formalised part of the NDIA's operational processes and procedures, to ensure clarity in capacity and coverage of individual government programs. This is recommended to include increased use of Carer Impact Statements during application and planning processes, along with increased transparent data, modelling and forecasting in public documents.
2. Formalised education on carers, relevant legislation and carer support services be incorporated and/or improved within NDIA training programs. This is recommended to be undertaken in consultation with Carers Associations and carers.
3. New and reformed data collection processes and reporting mechanisms be adopted, to better capture information about carers, separate to that of participants in the NDIS. This is recommended to be undertaken in consultation with Carers Associations and carers.
4. Follow up measures be established for support coordinators to take where services do not exist for participants, or fall through.
5. Attract, retain and train a workforce that is responsive to participant needs and delivers quality supports (Recommendation 15, NDIS Review Final Report).
  - The Australian Government should design and trial workforce attraction and retention initiatives (R15, Action 15.1)
  - The Australian Government should develop targeted and flexible migration pathways for care and support workers (R15, Action 15.2)
  - The Australian Government should develop an integrated approach to workforce development for the care and support sector (R15, Action 15.3)
6. Improve housing access for essential health workers in WA's regions, within industries and systems that people with disability and their carers navigate and use.
7. Support all people with disability to navigate mainstream, foundational and NDIS service systems (Recommendation 4, NDIS Review Final Report).
  - The NDIA should be the lead commissioner of a local navigation function to help people with disability find supports in their community and make the best use of their funding (R4, Action 4.1)
  - The NDIA should be the lead commissioner of a Specialist Navigation function for participants who have more complex or specific needs that cannot be reasonably met by general navigation support (R4, Action 4.2)
  - The NDIA should ~~ideally~~ adopt a joint commissioning approach to deliver local navigation support within a nationally consistent framework, developed in partnership with other relevant Australian government and state and territory government agencies (R4, Action 4.3)
  - The NDIA should design, test and implement the navigation function gradually, prioritizing continuity of support for participants and their families and a smooth transition for the workforce and market (R4, Action 4.4)

8. Strengthened market monitoring and responses to challenges in coordinating the NDIS market (Recommendation 13, NDIS Review Final Report):
  - The NDIS should progressively roll-out provider panel arrangements for allied health supports in small and medium rural towns or where participants face persistent supply gaps (R13, Action 13.2) – a local panel of local people.
  - All Australian governments through the Disability Reform Ministerial Council should agree and publish a provider of last resort policy to ensure participants have continued access to supports where markets fail (R13, Action 13.4)
9. Establishment of a respite supports category within the disability services system, which provides carers with certainty that they will receive timely and high quality respite services in accordance with assessed need. This should be inclusive of:
  - Provision of in-home respite support services that are local, timely and accessible.
  - Establishment of local carer retreats in regional centres.
  - Establishment of overnight respite options for children in regional centres.
  - A minimum target of respite be set for participants aligned with assessed needs.
10. Initiatives be explored to improve the Patient Assisted Travel Scheme suitability to rural, regional and remote WA and support of carers within the Scheme.
11. Increase service offerings be established in regional, remote and rural areas of WA for people with disability.
12. Regional transportation costs for NDIS participants and their carers be considered within the packages of regional NDIS participants.
13. Improve access to supports for First Nations participants across Australia and for all participants in remote communities through alternative commissioning arrangements (Recommendation 14, NDIS Review Final Report).
14. The establishment of initiatives that invest in a holistic model of support and connections to services for people with experience in the justice system with a health condition listed under the WA Carer Recognition Act 2010.

## 1.0 Introduction

Carers WA (CWA) welcomes the opportunity to provide feedback to the Joint Standing Committee on the National Disability Insurance Scheme's Inquiry into the NDIS participant experience in rural, regional and remote Australia.

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 can 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. This submission acknowledges and supports the focus of the Committee's Inquiry on the experiences of NDIS participants, and welcomes the examination of these experiences in rural, regional and remote Australia. This is particularly relevant to many carers, given that more than one third (37.4%) of primary carers have a disability themselves<sup>1</sup>. This submission is informed through the experiences and ongoing feedback of carers in Western Australia (WA).

For the purposes of this submission, 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. This care is not provided as part of a contract of service; for provision of voluntary work for a charitable, welfare or community organisation; or as part of a course of education or training<sup>2</sup>.

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<sup>1</sup> (Australian Bureau of Statistics, 2018)

<sup>2</sup> (Commonwealth of Australia, 2010)

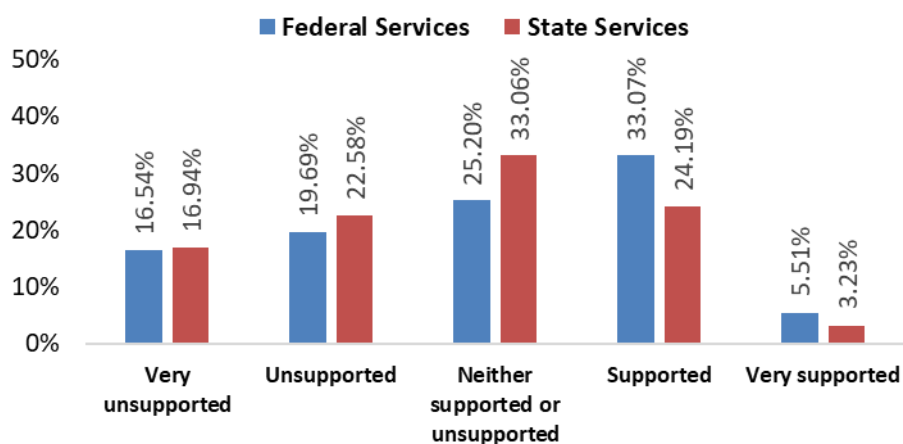
## 2.0 General Feedback

### 2.1 NDIS Participants and Carers in Rural, Regional and Remote Western Australia

Western Australia (WA) is the largest state in Australia, covering 2.646 million square kilometres and accounting for a third of the landmass of Australia<sup>3</sup>. This vast space and distance between towns and communities in rural, regional and remote WA presents unique and significant challenges for adequate service delivery, access to essential services and maintaining connection to community.

In particular, carers in regional, rural and remote areas of WA experience ongoing and increased service challenges, including with the NDIS. They also experience higher volumes of unmet carer support needs, as well as poorer health and higher instances of major illnesses.<sup>4</sup> In short, a high proportion of WA regional carers are in crisis. This results in carers having higher psychological distress, a greater impact of their caring role on work, more care tasks, as well as lower social support, recognition, work-life balance and self-efficacy<sup>5</sup>.

In WA, over half of carers surveyed (55.92%) said they felt unsupported or very unsupported by federal disability services. 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.



<sup>3</sup> (Tourism WA, 2024)

<sup>4</sup> (SAGE Design & Advisory, 2023)

<sup>5</sup> (SAGE Design & Advisory, 2023)

## Carers WA

In regional, rural and remote areas of WA, NDIA supports offered to NDIS applicants, participants and their carers are inadequate, especially when compared to their metropolitan counterparts. In many regional areas, Local Area Coordinators are often not present, meaning participants must directly contact the NDIA for support. In these areas also, awareness of services is an issue. For example, when undertaking community consultation in the Goldfields region, many members of the community were not aware that the NDIA office in Kalgoorlie was co-located with the Centrelink office.

Carers WA recommends that:

1. Carer identification, recognition, support and referral be a formalised part of the NDIA's operational processes and procedures, to ensure clarity in capacity and coverage of individual government programs. This is recommended to include increased use of Carer Impact Statements during application and planning processes, along with increased transparent data, modelling and forecasting in public documents.
2. Formalised education on carers, relevant legislation and carer support services be incorporated and/or improved within NDIA training programs. This is recommended to be undertaken in consultation with Carers Associations and carers.
3. New and reformed data collection processes and reporting mechanisms be adopted, to better capture information about carers, separate to that of participants in the NDIS. This is recommended to be undertaken in consultation with Carers Associations and carers.
4. Follow up measures be established for support coordinators to take where services do not exist for participants, or fall through.



## 2.2 Thin markets

Carers WA has been conducting extensive community consultation in WA's regions, to determine region-specific issues for carers, as well as engage with the community on potential solutions to these issues. Reoccurring common issues within these regions included a lack of awareness of locally available services and a lack of access to local services.

However, broader ranging issues in rural, regional and remote areas in WA are having substantial impact on service availability, access and awareness. These issues include ongoing impacts of COVID, housing shortages, workforce shortages, lack of access to transport and technology.

For example, in Kalgoorlie difficulties with accessing housing were raised by the community, attributed to high rental costs, a high cost of living, and the impact of the mining FIFO workforce. The result of these factors included members of the community having to relocate due to a lack of housing.

Challenges with housing were referenced in a recently produced paper by Urbis (on behalf of Kalgoorlie-Boulder Chamber of Commerce and Industry) entitled *Kalgoorlie-Boulder Land & Housing Position Paper*.<sup>6</sup> The paper described Kalgoorlie-Boulder as having a 'severe land and housing shortage which is having tangible, negative impacts on businesses, residents and the broader liveability of this regional centre'.

Contributing factors were outlined as including extremely low rental availability, low land availability, constrained long term land supply and limited infill development.<sup>7</sup> The report stated that these factors in turn were furthering economic and social challenges such as business viability; population retention; visitor attraction and driving social issues to unsustainable levels.<sup>8</sup>

In particular, the concern with population retention was that the lack of residential land and housing in the region was contributing to critical worker shortages within essential services.<sup>9</sup> This places additional strain on carers in the region as tasks which would have been performed by care workers for those they care for, now fall to them to complete. This also further impacts NDIS participants in the region as they are not able to access required services, even if they are funded in their package, due to these convoluted and intermingled issues which result in a lack of critical workers.

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<sup>6</sup> (Urbis, 2022)

<sup>7</sup> (Urbis, 2022)

<sup>8</sup> (Urbis, 2022)

<sup>9</sup> (Urbis, 2022)

Carers WA recommends:

5. Attract, retain and train a workforce that is responsive to participant needs and delivers quality supports (Recommendation 15, NDIS Review Final Report).
  - The Australian Government should design and trial workforce attraction and retention initiatives (R15, Action 15.1)
  - The Australian Government should develop targeted and flexible migration pathways for care and support workers (R15, Action 15.2)
  - The Australian Government should develop an integrated approach to workforce development for the care and support sector (R15, Action 15.3)
6. Improve housing access for essential health workers in WA's regions, within industries and systems that people with disability and their carers navigate and use.

### **2.2.1 Awareness of locally available services**

Carers and consumers in rural, regional and remote areas of WA experience difficulty with limited awareness of locally available services, with contributing factors including continuity of some services and continuity of staff. This impacts the ability of stakeholders to navigate services, as well as refer consumers and carers between services. Indeed, service providers in these areas raised that carers particularly sought advice on service navigation, and wanted the advice provided to be easily accessible and obtainable in multiple formats.

Carers WA recommends:

8. Support all people with disability to navigate mainstream, foundational and NDIS service systems (Recommendation 4, NDIS Review Final Report).
  - The NDIA should be the lead commissioner of a local navigation function to help people with disability find supports in their community and make the best use of their funding (R4, Action 4.1)
  - The NDIA should be the lead commissioner of a Specialist Navigation function for participants who have more complex or specific needs that cannot be reasonably met by general navigation support (R4, Action 4.2)
  - The NDIA should ~~ideally~~ adopt a joint commissioning approach to deliver local navigation support within a nationally consistent framework, developed in partnership with other relevant Australian government and state and territory government agencies (R4, Action 4.3)
  - The NDIA should design, test and implement the navigation function gradually, prioritizing continuity of support for participants and their families and a smooth transition for the workforce and market (R4, Action 4.4)

### **2.2.2 Local access to services**

In Australia, about 28% of its population live in regional, rural or remote areas with poor access to specialist health services.<sup>10</sup> Australians living in rural and remote areas experience higher rates of hospitalisation, death and injury. However, they also have inferior access to and less use of primary health services – than Australians in major cities.<sup>11</sup>

In regional WA, the finding which was of most concern and which is estimated to have the most impact, is a lack of local access to services. This included services which were not present in the region, those with access issues, and those which were becoming increasingly difficult to access.

#### Kalgoorlie and the Goldfields region

Carers and service providers in the WA Goldfields region report being forced to move to metropolitan areas to access healthcare; and accessing occupational therapy, or other allied health services. Where the family moving away works in these allied health services, worker shortages in these vital professions are exacerbated. One service provider aptly termed this as ‘when people get sick, they either move to access healthcare – or they die’.

Health services in the Kalgoorlie and Goldfields region were described as having a lack of availability, extensive waitlists and high costs for services. The community anecdotally provided examples of extreme situations undertaken to ensure access to healthcare, including: people with access to planes flying their children to Perth every fortnight for their occupational therapy appointments, due to the 2 year wait for these appointments in this region; doctors needing to be flown in from New Zealand in FIFO arrangements; and where allied health services have been flown in, reports of these costs being added to the cost of the appointment for families.

#### Albany and the Great Southern region

In Albany and the Great Southern region, the community reported substantial concerns around a lack of access to specialist services in the Great Southern, particularly in remote or outer areas. This was particularly true of CHSP services in remote areas, with some feedback being that clients were being told to relocate as some providers could not service higher level care in remote areas.

Specialist health services identified as lacking from the region, or which were at capacity, included: speech therapy; continence assessments; complex behaviour supports; paediatricians; occupational therapists; and Mental health services, including counselling. These were reported to be at capacity. The community also reported that a permanent Neurologist was needed in the Great Southern, as well as reduced neurology wait-times. These shortages were impacted by workforce issues such as continuity, staffing availability and pay.

Programs and services for children and youth were also reported as being needed, inclusive of more programs, supports and associated workers for children with disability.

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<sup>10</sup> (Australian Institute of Health and Welfare, 2023)

<sup>11</sup> (Australian Institute of Health and Welfare, 2023)

Broome and the Kimberley region

Community feedback indicated that there were little to no service providers in remote areas of the Kimberley, and limited access to services even in Broome.

This included support workers, allied health providers, etc. This made accessing supports for those needing them extremely difficult. This is significant for carers as these services reduce their caring responsibilities. Carers end up taking on a bigger role than they otherwise would have. This has contributed to substantial demand for respite and support for carers.

Carers WA recommends:

9. Strengthened market monitoring and responses to challenges in coordinating the NDIS market (Recommendation 13, NDIS Review Final Report):
  - The NDIS should progressively roll-out provider panel arrangements for allied health supports in small and medium rural towns or where participants face persistent supply gaps (R13, Action 13.2)- a local panel of local people.
  - All Australian governments through the Disability Reform Ministerial Council should agree and publish a provider of last resort policy to ensure participants have continued access to supports where markets fail (R13, Action 13.4)

## 2.3 Access to respite services

*'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

A significant and prevailing challenge experienced by carers in Australia, is tangible recognition of their caring role, themselves as carers, and appropriate support as part of this recognition.

While this challenge is well recognised and represented within the Recommendations of the Final Report of the Royal Commission into Aged Care, this is lacking in the recommendations of the NDIS Review Final Report. Indeed, Recommendations 1 & 3 specifically refer to the need for carers to have access to respite, and to have certainty of timely and high-quality supports. This need is ever more prevalent in rural, regional and remote WA, and is not just limited to carers of older people. Carers of people with disability also need access to respite and the ability to take a break.

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 worsened due to 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 older Australians and people with disability<sup>12</sup>. Access to respite for a carer can help them to have a healthy level of wellbeing<sup>13</sup>, 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.

Carers WA's consultations with regional communities has indicated that access to respite services in rural, regional and remote WA are limited, costly and have substantial waitlists.

### Kalgoorlie and the Goldfields region

The ability of carers to access respite from any service in the Goldfields region and in Kalgoorlie 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. Existing providers had either decreased their respite services, stopped taking bookings due to waitlist length, or were limited. At the time of consultation, this had resulted in there not being any available respite beds or in-home respite in Kalgoorlie.

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<sup>12</sup> (Myleck & Schirmer, 2023)

<sup>13</sup> (Myleck & Schirmer, 2023)

### Albany and the Great Southern region

In Albany and the Great Southern region, 50% of service providers consulted identified respite related needs as the biggest area of need in the area. This included the need for local carer retreats and respite options; in-home or homelike respite; overnight respite; affordable and available respite; respite options for children; and a high need for high-care respite beds. need for high-care respite beds.

While the need for these services is being strongly felt throughout all metropolitan and regional areas, consultations revealed a particularly pronounced lack of access to them in the Great Southern. This is reflective of the higher proportion of carers in this region, than in broader WA,<sup>14</sup> as well as a higher proportion of people aged over 65 (23.0%).

### Broome and the Kimberley region

One-third of service providers consulted in this region raised concerns about access to respite or opportunities for carers to have a break. Carers in remote communities were particularly flagged as being 'forgotten' and often having no access to respite.

Carers WA recommends the:

9. Establishment of a respite supports category within the disability services system, which provides carers with certainty that they will receive timely and high quality respite services in accordance with assessed need. This should be inclusive of:
  - Provision of in-home respite support services that are local, timely and accessible.
  - Establishment of local carer retreats in regional centres.
  - Establishment of overnight respite options for children in regional centres.
  - A minimum target of respite be set for participants aligned with assessed needs.

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<sup>14</sup> (Australian Bureau of Statistics, 2021)

### 3.0 Additional Barriers to Services

#### Transport

About 28% of the Australian population live in regional, rural or remote areas with poor access to specialist health services.<sup>15</sup> This is also coupled with poor access to transport in many of these areas.

In the Goldfields, the community raised issues with access to transport in the region, particularly for people with disability and for First Nations communities. Service providers raised that there were no maxi-taxis in Esperance, and very limited number of these in Kalgoorlie. A need was also identified by the community for additional transport resources for First Nations peoples to get back to Country.

In the Great Southern region, access to transport was also raised as a significant issue, especially for outer areas. In areas such as Denmark, service providers raised concerns around the lack of transport options, with people having difficulties to even travel ten kilometres. In Denmark, the community stated that there were no taxi services or TransWA, and very limited bus services.

Costs of transportation were also raised as a significant barrier when comparing regional and metropolitan costs. For example, for an appointment in metropolitan areas, costs of transportation may only include a taxi; whereas in regional areas this may include a support worker for the day, plus a full day or more of travel, and accommodation if needed. If a NDIS participant has allocations for travel within their package, this often does not consider the cost of regional transportation. Much of the travel allocation is hence exhausted on just one or two appointments.

Carers WA recommends that:

10. Initiatives be explored to improve the Patient Assisted Travel Scheme suitability to rural, regional and remote WA and support of carers within the Scheme.
11. Increase service offerings be established in regional, remote and rural areas of WA for people with disability.
12. Regional transportation costs for NDIS participants and their carers be considered within the packages of regional NDIS participants.

#### Communication

A significant barrier to access and use of NDIS services is communication difficulties. This may take the form of language gaps, different cultural understandings, overuse of acronyms and specialised terminology, etc. This can particularly be a barrier for First Nations communities and culturally and linguistically diverse communities when connecting to the NDIS, or building awareness of the NDIS.

This and other barriers may also result in belated engagement with the NDIS, or only having the opportunity to try to engage after the age of 65. This is especially a risk for rural and remote

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<sup>15</sup> (Australian Institute of Health and Welfare, 2023)

## Carers WA

First Nations communities, resulting in a lack of support for a person who may have been able to benefit from access to the NDIS, as well as their carer.

Due to these communication and other difficulties, there is also limited awareness of the NDIS in rural, regional and remote areas. Limited First Nations local area coordinators, NDIS & NDIA staff with lived experience, and First Nations and CALD medical professionals who can navigate the system and communicate it back to community – further exacerbate this issue.

Carers WA recommends:

13. Improve access to supports for First Nations participants across Australia and for all participants in remote communities through alternative commissioning arrangements (Recommendation 14, NDIS Review Final Report).

### Missed opportunities

While undertaking consultations in Broome and the Kimberley region, it was raised to Carers WA that there was a concerning lack of holistic services and support for people with experience in the justice system.

Young people exiting detention were raised as an example of this, with limited rehabilitation services or linkage of other needed services such as the NDIS being provided.

This is of relevance to carers due to the high prevalence of trauma, mental ill health and other health conditions in young people exiting the justice system, particularly for First Nations peoples (Heffernan, 2016). This prevalence means there is a higher likelihood of people with a health condition and with experience in the justice system having a carer.

Carers WA recommends that:

14. The establishment of initiatives that invest in a holistic model of support and connections to services for people with experience in the justice system with a health condition listed under the WA Carer Recognition Act 2010.



## 5.0 Conclusion

Should the Joint Standing Committee 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](mailto:policy@carerswa.asn.au).

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