Submission to the

NDIS Review

What we have heard: Moving from defining problems to designing solutions to build a better NDIS

September 2023

'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

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.

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1.0 Introduction

Carers WA appreciates the opportunity to provide feedback to the Independent Review Panel for the NDIS Review, in response to the report on *What we have heard: moving from defining problems to designing solutions to build a better NDIS.*

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 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.

This submission acknowledges and supports the primary focus of the NDIS on the needs and aspirations of people with disability. However, this focus also needs to encompass the carer/s a person with disability has chosen to have involved in their care, as well as ensuring the carer is also recognised and supported in line with the WA *Carers Recognition Act 2010.*

Over one-third (37.4%) of primary carers have disability, more than double the rate of non-carers (15.3%)[1]. Further, 46% of carers have one or more disabilities, health conditions or injuries that restrict their everyday activities. Carers often also do not have a choice becoming a carer, and also have lower wellbeing, as well as diminished economic and financial security than non-carers[2]. For carers who have disability, the caring role also further exacerbates disadvantage and discrimination, which also needs to be recognised within the NDIS and related systems.

This submission is informed by ongoing feedback from carers in WA, including:

- Targeted consultations for response to the Department of Communities' *Reforming WA's Disability Legislation Discussion Paper*. This included two hybrid carer-focused consultation sessions with the Department of Communities; an online survey that attracted 138 responses; individual feedback from carers; and feedback resulting from business-as-usual practices. Through these consultations, carers robustly expressed their concern with the lack of translation of disability legislation to practice, as well as the severely limited penalty and application of this penalty for ill-treatment of people with disability, and the lack of recognition and support for the carer a person with disability has nominated to be involved in their care. In addition, carers provided feedback on the NDIS, including on a range of recommendations for improvement.
- Targeted consultations for response to the federal Standing Committee on Social Policy and Legal Affairs' Inquiry into the recognition of unpaid carers. This included three hybrid consultations and an online survey which attracted 257 responses.

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[1] (Deloitte Access Economics, 2020)

[2] (Schirmer, Mylek, & Miranti, 2022)

2.0 General Feedback

2.1 Past recommendations

In December 2022, Carers WA provided a submission in response to the Parliamentary Joint Standing Committee on the NDIS' Inquiry into the Capability of the NDIA. Within this submission (available here), WA provided eight recommendations for improvement, which remain valid to the context of this consultation, including:

a) More one-on-one support be provided for access requests and pre-planning document preparation to NDIA applicants, participants and carers. The criteria for NDIS approval be clarified and the development of education for NDIA, NDIS and other relevant staff to ensure outcomes are clear and consistent.

b) Additional support and funding be provided for support coordination for plan management, particularly for participants new to the scheme or when circumstances have changed. We also recommend flexibility is built into plan management and engagement for changes in funding when required for plan management. The plan review process be reviewed, including provision of increased one-on-one support to carers and participants and reduction of time taken for plan reviews.

c) Communication and complaint processes within the NDIA and NDIS Quality and Safeguards Commission be reviewed to ensure effective outcomes from formal complaints, which are also communicated back to the lodger in a timely manner.

d) Increased options be provided for accessible childcare and school holiday programs for children with disability, as well as options to increase support for these services, either through the NDIS or an outside medium such as reform to the childcare subsidy.

e) 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.

f) 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.

g) 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.

h) NDIA investment in initiatives to combat thin markets, workforce challenges and shortfalls in service provision such as in respite services.

As such, it is recommended:

1. Carers WA's previous submission to the Parliamentary Joint Standing Committee on the NDIS' Inquiry into the Capability of the NDIA, and subsequent recommendations within this submission, be considered within this consultation and the wider NDIS Review.

2.2 Carer Recognition

> *'I am encouraged by the vision of a world where the role and contribution of unpaid carers is recognised and we have access to the quality support and services we need to live our own lives, focussing on issues such as our health and financial concerns along with how we may be supported while we are caring.' – response from a carer*

The *What we have heard* report states that 'support for families has largely been ignored'. This is also true of support for carers, recognition of carers and inclusion of carers within the NDIS.

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[3].

Carers WA recently commissioned independent analysis of the WA responses to the 2022 National Carer Survey. Mediation analysis was undertaken as part of this assessment, which found that **recognition had a significant direct effect on a carer's wellbeing[4].** In particular, this analysis found that **the more recognised and valued a carer felt by their community, service providers, family and friends – the higher their wellbeing became[5]**. In connection to this finding, social supports were also determined to have the greatest direct impact on carer wellbeing, and had a mediatory effect on the relationship between recognition and wellbeing – meaning that **improvements in a carer's social supports and levels of recognition could in turn reduce the impact of their caring role on their wellbeing[6].**

Further, feedback from carers indicates that better recognition of their caring role would have significant impact on their lives. On average, carers scored the impact of better recognition on their lives as a 9 out of 10, with 60% of respondents saying the impact would be a 10. Indeed, over 70% of carers responded that recognition was important or very important to them: in the workplace (77.23%); in health services (87.09%); in disability services (85.31%); in mental health services (86.35%); in housing and tenancy services (76.33%); in educational facilities (77.45%); and in financial support for carers (88.76%).

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[3] (Commonwealth of Australia, 2010)

[4] (SAGE Design & Advisory, 2023)

[5] (SAGE Design & Advisory, 2023)

[6] (SAGE Design & Advisory, 2023)

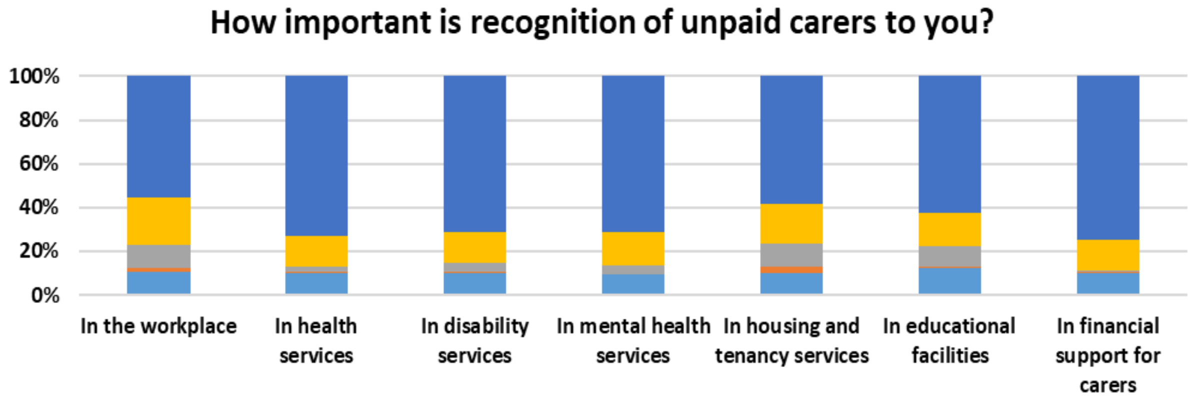

Figure 1 Importance of recognition to carers [7]

2.3 The meaning of recognition

> *'Recognition would mean more support for carers in a tangible way. We are very tired and always have more to do than there are hours in the day.' – response from a carer*

While the personal meaning of recognition varies from carer to carer, particularly for carers facing difficulties such as homelessness and severe financial challenges, several common themes include: acknowledgement of the difficulties and diversity of the caring role; practical demonstration of this acknowledgement through needed supports and sufficient financial assistance; assistance with service navigation and access; and time to take a break, accompanied with access to respite services.

2.3.1 Acknowledgment of the difficulties and diversity of the caring role

> *'That we are seen and valued. It can be (in my circumstance) very isolating which has a huge impact on the carer's mental health. I attribute the downward spiral directly to being 'lost' or invisible in society.' – response from a carer*

As outlined in section 1.0, the role of a carer comes at a great cost to the person's financial and general wellbeing. This was reinforced in recent consultations with carers and in an online survey undertaken to inform Carers WA's response to the federal Inquiry into Carer Recognition. Carers raised the personal costs faced in their caring role which rarely seemed to be fully acknowledged, such as loneliness; social isolation; impact on mental and physical wellbeing; financial impact; feeling that their role as a carer is not recognised as a legitimate role; feeling hopeless, unseen and unvalued.

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[7] (Carers WA, 2023)

> *'Acknowledgement of our existence - broadening the spotlight from the person requiring care, and focusing on the ripple effect of caring on others. Broader advocacy for those who care when those who care don't have the energy anymore. Raises the profile of carers in the general community, legitimising the role.' – response from a carer*

Carers also spoke of the lack of recognition for the diversity of caring roles, both for the amount of care being provided and for the demographic of the carer themselves. Carers spoke of the differences between a 24/7 caring role and a lighter caring role, as well as of the number of people which carers support, which can vary significantly.

> *'Better recognition by monetary and social, emotional supports for 24/7 carers. That is where the carer needs to support the loved one every minute of the day. These carers are very different to needing to give support a few hours a day.' – response from a carer*
>
> *'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*

This is in addition to the diversity of carers themselves, which range in age from young carers (8-25 years) and up, with each carer experiencing unique needs and experiences which differ by age, sexuality, gender, race and culture, including those for carers from Aboriginal and Torres Strait Islander communities. This diversity is not acknowledged in the WA Carers Recognition Act 2004, although it is touched upon in the Schedule for Australia's Carers within the federal Carers Recognition Act 2010. However, ongoing inconsistencies in the use of the term 'carer', as well as recognition of who is a carer, are indicative of opportunities for improved widespread clarity and consistency of the definition and awareness of the term 'carer'. This includes many instances of a lack of differentiation between parental roles, careworkers and carer (as defined in the Carer Recognition Act 2010).

Carers WA recommends:

2. Carers be better defined, recognized and included within the NDIS, in line with the definition under the federal *Carer Recognition Act 2010.*

2.3.2 Carer supports and sufficient financial assistance

‘Recognition sometimes seems like a catch phrase. I find that it has no noticeable impact on my daily carer role to two children with disabilities. Recognition means nothing without action and meaningful support. 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

Throughout consultations conducted by Carers WA, carers robustly expressed the need for carer recognition to go beyond just acknowledgement or a tick-the-box form of recognition, to more tangible recognition through needed supports and appropriate levels of financial assistance. This included that exclusion of adequacy of payments for carers from the scope of this Inquiry would result in a lack of holistic consideration of all forms of recognition for carers, including this more tangible form of recognition.

As outlined in Section 1.0, the caring role has significant impact on carers’ financial wellbeing, in lost wages and superannuation, as well as ongoing financial hardship. In fact, independent analysis of the WA results of the 2022 National Carer Survey indicated that the majority of carers in WA were receiving government payments, and that 57% of carers receiving government payments were living below the poverty line[8]. This in turn results in additional stress from the strain of struggling to make ends meet, as well as undertake a challenging caring role, with people living below the poverty line also more likely to experience family stress, housing issues, and poor health and psychological outcomes. Therefore, carers who receive government payments, of which there are many in WA, are at significant risk – this is a central concern to carer recognition and is of importance to 88.76% of carers[9].

Further, the need for reform on carer concessions is supported by the Final Report of the Senate Select Committee on Work and Care, which notes that ‘*income support payments are not fit for purpose for people trying to make a liveable income while caring for others and seeking more engagement with paid employment. The real value of carer payments have fallen behind*’.

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[8] (SAGE Design & Advisory, 2023)

[9] (Carers WA, 2023)

As such, Carers WA recommends that:

3. Adequacy of carer payments and economic security of carers be considered within the scope of this review, including:
    - Navigation of services to access financial support for carers;
    - Review of the level of the Carers Payment and Carers Allowance (as per Recommendation 30 of the Final Report of the Senate Select Committee on Work and Care[10]).
    - Superannuation guarantee on the carers payment (as recommended within *Caring Costs Us: The economic impact on lifetime income and retirement savings of informal carers*);
    - Addressing carer concession mechanisms which disincentivise carers returning to work, such as the low income threshold for the Carer Payment, the constant care rule, and the 25-hour rule. The latter mechanism limits Carer Payment participants to 25 hours of work activity per week (including travel time) to undertake training, education, unpaid voluntary work or paid employment before the level of their payment is affected. Carers WA recommends that this 25-hour restriction on work, study and volunteering be replaced with a 100 hour per month restriction on work only. This is Recommended Action 18.3 from the Productivity Commission Inquiry into Mental Health in 2020[11], and is a recommendation which Carers WA and other carer associations made to the Senate Select Committee for Work and Care in 2022.

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[10] (Commonwealth of Australia, 2023)

[11] (Australian Government Productivity Commission, 2020)

In addition to sufficient financial support, carers have expressed the need for recognition that supports carers to achieve their best self, and for '*governments, organisations and businesses (and the community in general)…[to] understand, respect and support my role as an unpaid carer so I can be the best I can for those I care for*'. This in itself reflects the fact that carers will often forget themselves in the midst of the caring roles that they undertake, seeking support for the benefit of those they care for, either directly or indirectly. To maintain their caring roles, and continue to offer the unpaid support which is of such benefit to their loved ones, the government, the health system and wider community – carers need to be supported to achieve their best self.

> *'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*

In particular, carers have said that they need:

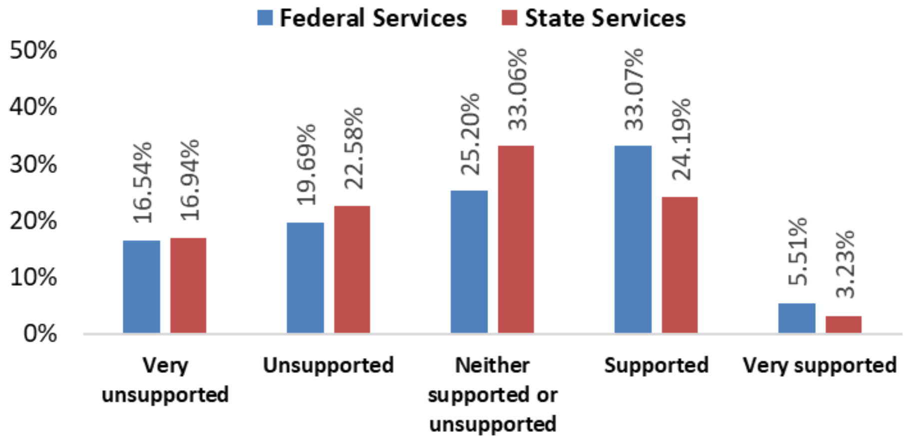
- Health and mental health support and proactive services for monitoring carers' mental health;
- Timely and local access to funded in-home and residential respite;
- Support for childcare, respite and vacation care for children with disability and complex needs;
- Time to take a break;
- Funded access to short breaks for carers;
- More access to free counsellors;
- Advocacy;
- Recognition and support of the caring role in the workplace, including through flexible work arrangements, carers leave (separate to personal leave entitlements);
- Support to navigate and access needed support for themselves and those they care for; and
- Recognition, validation, inclusion and credibility.

To assist in addressing these needs, Carers WA recommends:

4. A new proactive National Carer Strategy be developed to achieve vast and lasting improvements for carers in Australia, that embraces and implements the policy pillars of the Carers Australia Network, these being:
    - The economic security of carers;
    - Health and wellbeing of carers;
    - Carer recognition, representation, and inclusion.

2.4 Reasonable and necessary

Within Carers WA's feedback survey on disability legislation, respondents were asked how supported they felt by disability services at a Federal and State level. **Over half of survey respondents (55.92%) said they felt unsupported or very unsupported by Federal disability services, and 39.52% felt the same towards State disability services.** This overwhelming feeling of being unsupported by disability services stems from a lack of clarity in NDIS eligibility criteria (i.e. reasonable & necessary); gaps in supports for people with disability and carers outside the NDIS; and gaps in supports for participants and carers within the NDIS.



The *What we have heard* report recognised that the 'reasonable and necessary' criteria used by the NDIS for funding decisions, is not well defined. It is also recognised that this results in many issues within the operation of the scheme, including inconsistent decisions and negative experiences in planning. This results in additional stress for carers, participants and applicants who navigate the processes of the NDIS and extensive time delays for participants to get services in place – if they are granted funding.

Due to the extensive impact of the lack of clarity of the 'reasonable and necessary' criteria, Carers WA recommends:

5. The defining and practice of this criteria be undertaken through a collaborative co-design process (including people with disability and carers), and be backed by extensive practical awareness and education campaigns.

2.5 Support for children

> *'I don't even know where to start. I'm at a loss. I feel humiliated at my very existence and I'm scared for the future of my children to be living in a society who treats people who ask for help with neurodiversity this way.' – response from a carer*

Carers WA recently provided a submission (available here) to the Department of Social Services, in response to The Early Years Strategy discussion paper, which made several recommendations of relevance to this consultation.

Informal carers of young children will be amongst those experiencing the highest impacts of a caring role, in particular due to the increased amount of time that their caring role may be for. Informal carers of young children will often not be able to return to work for longer, or take a break. They will also experience high medical costs, complex systems and long and frustrating waitlists, as they work to advocate strongly for their child, at a detriment to their own wellbeing.

> *'Although I appreciate the support that we currently have there is more needed. People with severe disability are not included even in the disability sector, they are put in the "too hard" basket and too often I am told our services are not appropriate for your child try elsewhere. Providers can choose who they service and take on "easier clients" We are told by providers that our child needs 1:1 but NDIS doesn't provide funding for 1:1 so our child is disadvantaged in that respect as well, funding runs out quicker. There are 1 or 2 providers that will work with children with high needs but have limited places available as there is a huge demand, very difficult to get a spot and often put on a waitlist.' – response from a carer*

2.5.1 Access to supports for children with disability

Carers of children with complex needs have limited options when it comes to accessing childcare for young children, with many carers reporting not being able to access such services or have the option to return to work until their child enters the public school system. The *Early Years Strategy discussion paper* raised the importance of the first 1,000 days, and the consequences for if a gap emerges and is not closed in the first 5 years of life – a lack of access for children with high care needs to childcare programs which support their development and individual needs, is such a gap.

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 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.

Carers WA recommends:

6. Increased options be provided for accessible and inclusive childcare and school holiday programs for children with disability, as well as options to increase support for these services, either through the NDIS or an outside medium such as reform to the childcare subsidy.
7. Organisations involved in early childhood education and support be appropriately resourced for early identification and support of carers of young children. This should also include establishing and strengthening referral pathways to relevant carer support organisations in each state and territory. This is particularly of importance as carers of this age group may be in a caring role for the next 30-40 years or more.

This would in turn support carers of children with disability to have the option of returning to the workforce earlier than when their child enters the school system, as well as provide increased opportunities for carers to participate in other economic, social and community opportunities. The importance of supporting carers through such an outcome is outlined within the *Carers Recognition Act 2010* and *The Statement for Australia’s Carers*.

Carers WA also recommends:

8. An increased focus on reducing complexity in system navigation, particularly for informal carers who will be navigating multiple complex systems at once to ensure their child is as supported as possible.

2.5.2 Cost, access to and availability of healthcare for children and families

In WA, costs of even general healthcare for families are can often be high, with significant reductions in the number of general practitioners (GPs) who are bulk billing and high costs of private specialists. Carers report that GPs which used to bulk bill for concession card holders, have now moved to policies such as having gap fees for concession card holders aged 16-64.

Public waitlists for paediatricians in WA can be significant, extending over 24 months wait-time for an initial appointment. Carers report resorting to obtaining a diagnosis for their child through the private system, but the cost of this is high, with costs reported of $5,000-$6,000 just for diagnosis.

Even for private paediatricians, waitlists can be long, and due to demand many paediatricians are either not accepting bookings, or only accepting restricted or condition-specific bookings.

These difficulties and costs associated with obtaining a diagnosis for a child, as well as wait times for other public health services, circumnavigate the benefits of early intervention. Although it may have been identified that a child may need some extra supports, the two years they spend on a waitlist waiting for diagnosis or regular services, is two extra years they are falling behind.

Carers WA recommends that:

9. Reforms be investigated to alleviate wait times and costs of specialists for children.

2.6 Regionality

> *'We need supports in remote and regional WA full stop. We have no access to allied supports because there are none. Instead of concentrating on the benefits of FIFO work, the federal and state governments should focus on building communities and attracting allied healthcare staff to the regions so our disabled and vulnerable populations don't fall even further behind their metro peers.' – response from a carer*

WA and Queensland hold the greatest proportions of carers that have the highest needs, at 24% of carers and 25% of carers in each state respectively[12]. This was indicated by independent analysis of national carer responses from the 2022 National Carer Survey. The analysis described these carers as having higher psychological distress, a greater impact of their caring role on work, have more care tasks, as well as lower social support, recognition, work-life balance and self-efficacy[13]. There was also a higher level of carers with high needs in regional areas than metropolitan areas[14], in the midst of heightened and pronounced challenges which carers in regional areas have in accessing services and support for themselves and those they care for, along with issues with housing and transport.

Carers WA has been engaging and consulting with carers and service providers in regional areas to re-connect with carers following the COVID-19 pandemic, as well as identify region-specific systemic issues and solutions, in collaboration with regional communities. Carers and service providers in regional areas in particular experience significant issues with access to services, including in-home and residential respite. This is in part due to staffing shortages and a lack of housing for staff in regional areas of WA.

While Carers WA is engaging with regional communities through regional roadtrips, regional coordinators and a significant number of partnerships with local service providers, more needs to be done to address the unique barriers of regionality for carers in states like WA and Queensland.

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[12] (SAGE Design & Advisory, 2023)

[13] (SAGE Design & Advisory, 2023)

[14] (SAGE Design & Advisory, 2023)

Carers WA recommends:

10. Increased investment in ensuring services which carers access and navigate are timely and locally available, including access to funded in-home and residential respite care.
11. Increased investment in ensuring allied health services are timely and locally available.
12. Increased investment in regional coordinators and services for carers.

2.7 Quality and Safeguarding

> *'For reporting to be followed. And believed. Especially when you have witnesses when it involves children. There should also be a register where people who have committed acts of crime against people with disabilities should be free to see. That way anyone can check before hiring or enrolling for a child or person with disabilities. There should also be a group who monitors support workers who abuse, neglect etc. A lot of the time parents write that they have seen or took photos whilst out, of the support worker not doing the right thing, that's very concerning. We should be protecting our loved ones.' – response from a carer*

Carers consider safeguarding and penalties for offences involving the ill-treatment of people with disability, to be of extreme importance. Within the context of WA state legislation, carers have described 'a $4,000 penalty or 12 months imprisonment is an insult to people with disability who are the most vulnerable in the community'.

Carers WA recommends:

1. The following safeguards be considered within the context of the review of the NDIS and solutions:
   - An independent government body or 'watchdog' tasked with checking in and ensuring people with disability feel safe where they are living and are able to speak for themselves.
   - Improved training, screening and monitoring of care workers and organisations.
     - Inclusive of training for care workers on life skills such as nutrition and food safe practices, to ensure the people they are caring for are being done so appropriately.
   - Increased fines and punitive measures against offenders, more accessible complaint processes and improved data sharing and collation between state and federal agencies of offenders.
   - A publicly available register of care workers and organisations who have committed crimes against people with disability, and an organisation to monitor these crimes, particularly if concerning children or elder abuse.
   - Greater awareness and training on identification of coercive control, and how to respond to and report it.

2.8 Complaints

Carers WA's survey results indicated that many carers were not sure of the complaint processes available to them or those whom they care for, indicating a need for greater awareness of complaints processes. Feedback revealed that where complaints processes were known, the onus fell on the person with disability or carer to make a complaint, with complaint outcomes that were limited or leave the complainant feeling 'brushed off'. If the complainant wished to remain anonymous, facilities to investigate became even more limited with less chance of an appropriate outcome. Carers describe being scared to submit a complaint to the organisation they are complaining about, due to fear of repercussions to those they care for during the next hospital or health practitioner visit.

Carers also reported complaint processes often not being accessible for themselves or those they cared for. As such, it is recommended that:

1. Initiatives to make complaint processes more accessible and transparent be implemented, including:
    - More advocates for people with disability and carers;
    - regular check-ins with people with disability;
    - a dedicated organisation, hotline and/or online process for complaints;
    - an online anonymous complaints process to combat the risk of retribution;
    - non-internet based options for complaints to provide for complainants without the access, desire or ability to use or navigate the internet; and
    - information and self-advocacy to increase awareness of complaints processes amongst people with disability, carers and families.

2.9 Improve opportunities for community and lived experience views to be shared

> *'I'm more than happy to provide feedback except I'm so exhausted, traumatised, broke and time poor. My children need their mother and my family has been torn apart and we are doing all we can to save it. They win right?'*

Carers raised the need for systemic change through ensuring ongoing and increased opportunities for open conversations and submissions with people with lived experience of disability and of caring for someone with disability. Further, conversations and consultations were recommended to be available in a range of formats to ensure increased representation of people with disability and carers. i.e. online and paper surveys; hybrid consultations (face-to-face and online); one-on-one consultations.

In addition, this lived experience was recommended to be included at all levels of government structures and policy making, as well as in decision making roles. It was also suggested that there be initiatives such as local forums on a regular basis for people with lived experience to contribute their views, which then report to the Minister, as well as permanent disability officers within local governments.

However, while increased opportunities for consultation is recommended, this needs to be accompanied by measures to ensure people with lived experience have the time and capacity to participate in them, as well as be renumerated for their contribution of their lived experience. For carers, increased support and regular check-ins are also needed to reduce the chance of burnout and increase their ability to stay in their caring role, including increased access to respite.

Carers WA recommends:

1. Increased investment in employment opportunities for people with lived experience of disability and of being a carer.
2. Increased investment in upskilling organisations to be better workplaces for people with disability and carers. I.e. through initiatives such as the Carer Friendly Employers program.
3. Ensuring ongoing and increased opportunities for open conversations and submissions with people with lived experience of disability and of caring for someone with disability, with appropriate renumeration and support to be able to contribute.
4. Increased investment in support for carers which enable them to take a break, including in-home and residential respite, as well as social support initiatives.

Conclusion

Should the Review Panel 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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