

Submission to the

Australian Government

Department of Social Services

The Australian Government response to the Royal Commission into Violence, Neglect and Exploitation of People with Disability

January 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.

Carers WA acknowledges the Traditional Owners of country throughout Australia and recognises their continuing connection to land, waters and community. We pay our respects to them and their cultures; and to Elders both past and present.

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Table of Contents

	Summary of Recommendations	.1
	1.0 Introduction	.2
	2.0 Recognition of carers	.3
	3.0 Definition of a carer	.6
	4.0 Clarity and detail	.6
	5.0 Conclusion	.7
E	Bibliography	.8

Summary of Recommendations

- Carers be recognised, consulted and included as partners in care within the development of the Disability Rights Act and other initiatives recommended by the Commissions, with recognition of the role that carers can play in the lives of people with disability where they have been nominated to do so.
- 2. The *Carer Recognition Act 2010* (Commonwealth) be strengthened into a rights-based Act (noting that a review is presently underway).
- 3. Carer identification and referral pathways be established, strengthened and clearly defined within the services they navigate and use.
- 4. A clear and consistent definition of carer be included within the Disability Rights Act and other initiatives recommended by the Commission.
- 5. Further clarity and detail be provided on the Department of Disability Equality and Inclusion and portfolio. We also recommend the inclusion of carers and carer associations in the development of policies, programs and services which will have impact on carers.

1.0 Introduction

Carers WA (CWA) welcomes the opportunity to provide feedback to inform the Australian Government response to the final report published by the Disability Royal Commission into Violence, Neglect and Exploitation of People with Disability (the Commission). We commend the Commission's extensive consultative work over its term and transformation of the invaluable experiences of the people who provided feedback, into the recommendations and content of the final report.

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 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 primary focus of the Commission's Final Report on the rights of people with disability and welcomes the intent of the report, in light of changes to the disability landscape over the past decade and the significant need for improvements to the rights of people with disability. This is particularly relevant to many carers, given that more than one third (37.4%) of primary carers have a disability themselves.¹ This submission is informed through the experiences and ongoing feedback of carers in Western Australia (WA).

¹ (Australian Bureau of Statistics, 2018)

2.0 Recognition 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

Recognition, identification and inclusion are significant issues for many carers across Australia, adversely impacting on a carer's ability to both perform their caring role to the best of their ability and be appropriately supported whilst doing so. Whilst these issues have shown some improvement over the past 15-20 years with the adoption of Carer Recognition Acts at State, Territory and Federal levels, much work remains to be done to ensure inclusion and recognition of carers – as well as the voices of carers. CWA notes the lack of recognition in the report of the diversity of carers, namely carers from first nations and indigenous communities, culturally and diverse backgrounds and LGBTIQ+ carers.

Carers WA is pleased that carers have been recognised within some recommendations of the Commission's Final Report, including within:

- Recommendation 4.11 in relation to consultation with people with disability and their 'families, carers and supporters of people with disability';
- Recommendation 5.5: inclusion of the 'views and experiences of people with disability, as well as those of families and carers of people with disability'.
- Recommendation 5.5: 'partnering with a diverse range of people with disability, and their families and carers, to develop advice and key reports'.
- Recommendation 5.6: establishment of 'a portfolio responsible for the disability and carers policies and programs currently the responsibility of the Social Services portfolio'.
- Recommendation 5.6: 'a Department of Disability Equality and Inclusion, responsible for the national disability and carers policies and programs that are currently the responsibility of the Department of Social Services.'
- Recommendation 7.5: 'commence transition planning in year 9 in collaboration with students, their parents and carers to help students define and articulate their goals and aspirations beyond school.'

However, we are disappointed at the limited recognition of the needs of carers themselves throughout the remainder of the Final Report, as well as of much needed referral pathways to carer supports.

Recognition has a significant direct effect on a carer's wellbeing. The more recognised and valued a carer feels by their community, service provider, family and friends – the higher their wellbeing becomes. Improvements in a carer's social supports and levels of recognition can reduce the impact of their caring role on their wellbeing.²

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%).³



How important is recognition of unpaid carers to you?

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 arise, including: 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.⁴

² (SAGE Design & Advisory, 2023)

³ (Carers WA, 2023)

⁴ (Carers WA, 2023)

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.⁵

This need is well reflected through the inclusion of carers in relevant government documents, such as Policy Priority 3 of the Personal and Community Support Outcome in Australia's *Disability Strategy 2021-2031* (the Strategy). This Priority outlines that the role of informal support is to be acknowledged and supported, recognising the importance of carers for many people with disability. Informal supports are recognised within this Policy Priority as important to supporting and enriching the lives of people with disabilities, with subsequent acknowledgement and support of these informal supports also able to lift the participation in community life of people with disability. Further, the role that informal advocates such as carers can play is also recognised, with the Strategy noting:

'In addition to providing practical and emotional support, those providing informal support can represent the interests and rights of the person they support' and the inclusion of a quote from Carers NSW 'informal carers can also be key sources of information and often play the role of advocate for the person they care for'.

To achieve better recognition and support of carers, Carers WA recommends:

- 1. Carers be recognised, consulted and included as partners in care within the development of the Disability Rights Act and other initiatives recommended by the Commissions (should these be adopted by the Australian Government), with recognition of the role that carers can play in the lives of people with disability where they have been nominated to do so.
- 2. The *Carer Recognition Act 2010* (Commonwealth) be strengthened into a rights-based Act (noting that a review is presently underway).
- 3. Carer identification and referral pathways be established, strengthened and clearly defined within the services they navigate and use.

⁵ (Carers WA, 2023)

3.0 Definition of a carer

While Carers WA is pleased that a definition of the term 'carer' has been included within the Commission's Final Report, we are concerned that the brevity of the definition will result in the continuation of ongoing confusion and issues over what a carer is, self-identification as a carer, and identification of carers by services.

The definition included in the report does not expand that carers are not volunteers or paid workers, nor does it link back to the present legislated definition of carer within the federal *Carer Recognition Act 2010.* Carers WA believes this has been a missed opportunity to clearly identify and define what and who a carer is.

Carers WA recommends that:

4. A clear and consistent definition of carer be included within the Disability Rights Act and other initiatives recommended by the Commission (should these be adopted by the Australian Government).

4.0 Clarity and detail

Recommendation 5.6 of the Final Report refers to the establishment of 'a portfolio responsible for the disability and carers policies and programs currently the responsibility of the Social Services portfolio', as well as 'a Department of Disability Equality and Inclusion, responsible for the national disability and carers policies and programs that are currently the responsibility of the Department of Social Services.'

Given the impact that this will have on carers and carer associations across the country, Carers WA recommends:

5. Further clarity and detail be provided on this Department and portfolio. We also recommend the inclusion of carers and carer associations in the development of policies, programs and services which will have impact on carers (should this recommendation be adopted by government).

5.0 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 <u>policy@carerswa.asn.au</u>.

Bibliography

- Australian Bureau of Statistics. (2018). *Disability, Carers and Aging Australia*. Retrieved from www.abs.gov.au: https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release#carers
- Carers WA. (2023). *Carers WA Policy Submission to the federal Inquiry into carer recognition.* Perth: Carers WA.

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