



**Submission to the  
Australian Government  
Department of Health and Aged Care**

**Mental Health Lived Experience Peak Bodies –  
Family/Carer/Kin Peak Body**

**October 2023**

## 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.

## Enquiries

Carissa Gautam

Systemic Policy Officer

[Policy@carerswa.asn.au](mailto:Policy@carerswa.asn.au)

Carers WA

182 Lord Street

PERTH WA 60000

Phone: 1300 227 377

Fax: (08) 9228 7488

Email: [info@carerswa.asn.au](mailto:info@carerswa.asn.au)

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## Key Recommendations

1. Inclusion of a directive in Grant Guidelines for active collaboration on key issues with peak carer organisations at a federal, state and territory level.
2. The family/carer/kin peak body to have a strong focus on recognising and supporting the unique needs of mental health carers, separate to the needs of the people they care for.
3. The inclusion of wording and a definition of mental health young carers within the next stages of the development of both peak bodies.  
i.e. **Mental Health Young Carer** – a young carer is a carer aged 8-25 years, who has lived experience of caring for a person with mental ill health.
4. Young carers be included within the specific cohorts proposed in Priority 2, and included under the Principle of 'Valuing diversity and promoting inclusion'.
5. The inclusion of recognition of the unique challenges of young carers from an Aboriginal and Torres Strait Islander background, CALD young carers and LGBTQI+ young carers.
6. Carers caring for multiple people and/or for people with multiple health conditions or comorbidities, are also recognized and included in the scope of this peak body.
7. Inclusion within the Grant Guidelines that the funding organisation must have experience with service provision to families/carers/kin in regional areas, or reaching into regional areas.
8. Recognition and support of carers be replicated across the systems that carers navigate and use.

## 1.0 Introduction

Carers WA welcomes the opportunity to provide feedback to the federal Department of Health and Aged Care (the Department), in response to its discussion paper on *Mental Health Lived Experience Peak Bodies – Family/Carer/Kin Peak Body*.

Carers WA is the peak body for carers in Western Australia, with a 26-year history of advocating for an improved quality of life for carers, inclusive of mental health carers. Carers WA is also the primary service provider for carer-specific services in WA, including Carer Gateway, the Carers in Employment program, Carer Representation program, Carer Wellness at Home, Prepare to Care Hospital Program, and the Young Carer program. Indeed, 10% of the carers with Carers WA have identified having lived experience of caring for someone with mental ill health. This submission is informed through these experiences and ongoing feedback from carers.

We would like to firstly commend the Productivity Commission on its strong focus on recognising and supporting mental health carers within its final report on the *Inquiry into Mental Health*. We would also like to recognise the Department of Health and Aged Care for its work thus far towards establishing two new independent mental health lived experience peak bodies, as well as the realisation of Recommendation 22.4 of the Inquiry's final report.

As a strong advocate of embedding lived experience within process and policy design, Carers WA is supportive of the intent of the mental health lived experience peak bodies. It is in this spirit that we offer the following feedback and recommendations, to ensure mental health carers are adequately represented and supported within the scope of this peak body.

## 2.0 Integration and collaboration

### *What does recognition mean to WA carers?*

*'Appropriate acknowledgement, which is then practically demonstrated in actual needed support, and not just financially but also in regards to carer health and wellbeing and importantly with navigating the system (as we are dealing with multiple 'households' and everything associated with them - our own and the person we care for). Timely access to services, more efficient and streamlined processes, information in one spot (the amount of times I've had conflicting info or been provided with info on services from other people that is not obvious on any website anywhere), better access to respite care. All of this assists the carer to continue with working as well - this for me is my sole income (I have no other family support). I have steadily reduced my work hours and need to reduce these further which I'm not sure work will accommodate - and this has not only reduced by income but my superannuation too.'* – feedback from a carer

Carers WA believes that the establishment of a mental health lived experience peak body for family/carers/kin will offer a positive focus to an area of health which often suffers from much stigmatisation. However, to maximise this peak body's effectiveness, the establishment and operation of it in practice needs to be in close alignment and partnership with existing peak bodies in this space.

In the case of carer organisations across Australia, there are many overlapping issues of relevance to the mental health space which would be of benefit to all peak bodies to collaborate on to share knowledge and experience. This would also be of benefit to ensuring the family/carers/kin peak body is 'responsive to evolving needs of diverse lived experience communities', as outlined within Priority 3 of the discussion paper.

Indeed, a lack of integration between and across services contributes to a primary issue that both carers and consumers experience, this being navigation of services. In WA regional areas in particular, constant movements in staff, services and funding – add another layer of complexity to navigation of services. This is on top of other region-specific issues such as thin markets and remoteness.

This issue is so prevalent that Carers WA has developed a Through the Maze Experiential Simulation Training, to build awareness amongst students and service providers of the caring journey. The purpose of this training is to provide participants with a deeper understanding and insight into some of the challenges and barriers carers and consumers face throughout their journey/roles. Real life scenarios are used to throw the participant into the world of a consumer or carer in navigating services, followed by a deeper discussion at the conclusion of the activity. This activity, which is also provided as a Carers WA staff induction activity, results in participants experiencing an extreme moment of clarity and understanding, of what consumers and carers have to deal with every single day with accessing and navigating services.

While the discussion paper seeks feedback on membership also including organisations representing families/carers/kin, state representatives and other organisations; this needs to go beyond just inclusion in membership. To better align with other organisational peaks, including carer peaks, Carers WA recommends:

1. Inclusion of a directive in Grant Guidelines for active collaboration on key issues with peak carer organisations at a federal, state and territory level.

### **3.0 A focus on carers**

Carers have a much higher risk than the average Australian of poor wellbeing, high psychological distress and poor health.<sup>1</sup> In addition, carers are three times as likely to regularly experience loneliness, which if not addressed has serious consequences for a person's mental and physical health. This can include the development of depression, alcohol abuse and sleep problems.<sup>2</sup>

Carers WA is supportive of the creation of opportunities for the two peak bodies to work together on common issues, as outlined in Priority 4 of the discussion paper. However, we would like to strongly emphasise the need for the family/carer/kin peak body to have a strong focus on recognising and supporting the unique needs of mental health carers, separate to the needs of the people they care for. This point is made because carers often selflessly focus primarily on the needs of the people they provide care for, which can be at a detriment to their own wellbeing and mental health.

2. The family/carer/kin peak body to have a strong focus on recognising and supporting the unique needs of mental health carers, separate to the needs of the people they care for.

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<sup>1</sup> (Centre for Change Governance and NATSEM, University of Canberra, 2021)

<sup>2</sup> (Centre for Change Governance and NATSEM, University of Canberra, 2021)

### 3.1 Young Carers

Within the mental health space, young carers are often viewed as consumers, and not recognized as carers as well.<sup>3</sup> While Priority 1 within the discussion paper states that membership should include ‘*young people and children who might provide support to family members, chosen family, friends and/or kin*’,<sup>4</sup> it does not give definition or scope to these young people and children. This is vital to improving recognition and support of young carers.

Carers WA is supportive of targeted membership and identified cohorts to ensure appropriate representation of the listed cohorts under Priority 2 in the discussion paper, as well as the inclusion of the principle of ‘valuing diversity and promoting inclusion’ within specified processes and procedures. However, although ‘children, youth and/or young people’ are listed under specific cohorts within Priority 2 of the discussion paper, young carers are absent from this list. This exclusion within a peak body for carers further exacerbates the lack of identification and support of young carers,<sup>5</sup> particularly for young carers who are hidden or experiencing additional layers of disadvantage or social exclusion. This includes young carers from an Aboriginal and Torres Strait Islander background, CALD young carers and LGBTQI+ young carers – all of which experience their own unique challenges separate to those of other young carers.

Inclusion of young carers in the membership of the peak body is also an area of recommended collaboration with carer organisations. For example, Carers WA has recently established a Young Carer Advisory Network to feed into policy and service design.

As such, Carers WA recommends:

3. The inclusion of wording and a definition of mental health young carers within the next stages of the development of both peak bodies.  
i.e. **Mental Health Young Carer** – a young carer is a carer aged 8-25 years, who has lived experience of caring for a person with mental ill health.
4. Young carers be included within the specific cohorts proposed in Priority 2, and included under the Principle of ‘Valuing diversity and promoting inclusion’.
5. The inclusion of recognition of the unique challenges of young carers from an Aboriginal and Torres Strait Islander background, CALD young carers and LGBTQI+ young carers.

### 3.3 Recognition of the diversity of caring relationships

Carers often experience difficulties with some services when the person they care for has multiple health conditions, hence not fitting into the box the service is funded or directed to provide services for. This also exists within the mental health space.

Carers WA supports the statement in Priority 1 around ‘remaining inclusive of broader or intersecting lived experiences.’ This is important to ensure carers caring for multiple people

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<sup>3</sup> (Smith, Blaxland, & Cass, 2011)

<sup>4</sup> (Australian Government Department of Health and Aged Care, 2023)

<sup>5</sup> (Smith, Blaxland, & Cass, 2011)

and/or for people with multiple health conditions, are also recognised and included in the scope of this peak body.

6. Carers caring for multiple people and/or for people with multiple health conditions or comorbidities, are also recognized and included in the scope of this peak body.

#### 4.0 Regional and remote carers

*'More support services in regional areas. Inclusion of other areas of caring (my situation is caring for my younger siblings as their parents can't due to mental health and drug dependency issues). I've not been able to find any support either financial or otherwise.'* – feedback from a carer

In WA, 24% of carers are in crisis, resulting in higher psychological distress, a greater impact of their caring role on work, more care tasks, lower social support, recognition, work-life balance and self-efficacy<sup>6</sup>. This is particularly prevalent in WA regional areas, 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. This is inclusive of mental health services, as well as lack of access to essential health services, which results in carers having to fill the gaps in services.

The discussion paper includes 'people from rural, regional and remote areas' within its list of specific cohorts, but does not include detail around consideration of the unique and region-specific challenges faced by regional carers. Given that 28% of the Australian population resides in regional areas, or 7 million people,<sup>7</sup> the operation of the peak body for families/carers/kin is recommended to include this consideration and experience.

Carers WA recommends:

7. Inclusion within the Grant Guidelines that the funding organisation must have experience with service provision to families/carers/kin in regional areas, or reaching into regional areas.

#### 5.0 Recognition of carers across systems

*'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.'* – feedback from a carer

Carers WA is supportive of the intent of the mental health lived experience peak bodies, but believes that this intent must be mirrored throughout all the systems that carers navigate and use. There is a prevailing lack of recognition of carers amongst many of these systems, as well as of the unique barriers carers experience. This is reflected in 63.47% of carers reporting a need for further recognition of carers.<sup>8</sup>

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<sup>6</sup> (SAGE Design & Advisory, 2023)

<sup>7</sup> (Australian Institute of Health and Welfare, 2023)

<sup>8</sup> (Carers WA, 2023)



Recognition has been found to have a significant direct effect on a carer’s wellbeing. Indeed, the more recognised and valued a carer felt by their community, service providers, family and friends – the higher their wellbeing became<sup>9</sup>. In connection to this finding, social supports have also been determined to have the greatest direct impact on carer wellbeing, having 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<sup>10</sup>.

Carers report that better recognition of their caring role would have a significant impact on their lives. Over 70% of carers surveyed report 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%).<sup>11</sup>

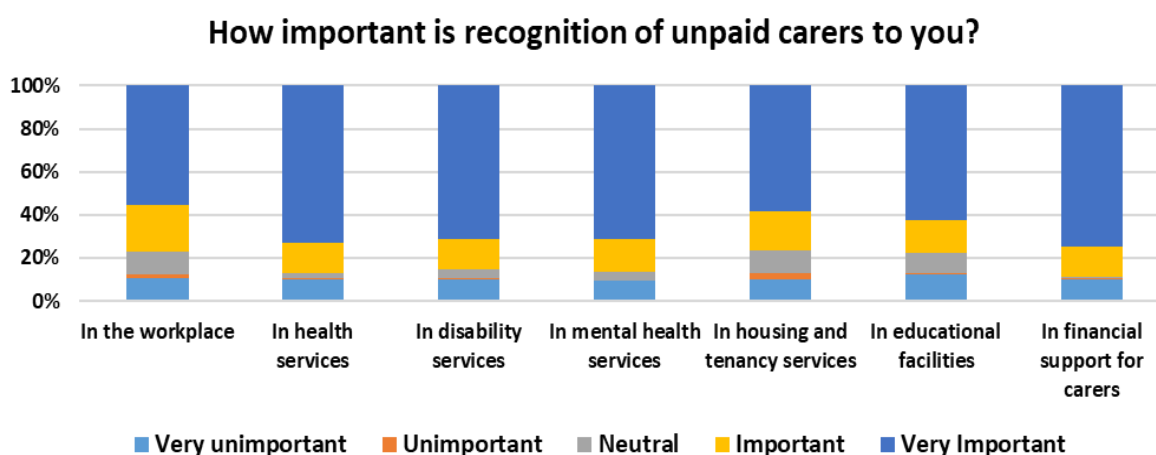


Figure 1 Responses froms online survey conducted by Carers WA<sup>12</sup>

8. Recognition and support of carers be replicated across the systems that carers navigate and use.

## 7.0 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](mailto:policy@carerswa.asn.au).

<sup>9</sup> (SAGE Design & Advisory, 2023)

<sup>10</sup> (SAGE Design & Advisory, 2023)

<sup>11</sup> (Carers WA, 2023)

<sup>12</sup> (Carers WA, 2023)

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