



**Feedback on the Co-Design of the National Mental Health
Lived Experience Family/Carer/Kin Peak Body**

October 2023



About Carers Tasmania

Carers Tasmania is the Peak Body representing the more than 80,000 informal carers (hereafter carers) in the state.

Carers Tasmania's vision is for an Australia that values and supports carers.

Our mission is to work to improve the health, wellbeing, resilience and financial security of carers and to ensure that caring is a shared responsibility of family, community, and government.

Our values drive everything we think, say, and do.

- **Carers first** – we listen to what carers need, commit to their desired action plan, and deliver results that matter most to carers
- **Care in all we do** – we care for our work, about each other, about Tasmania's family and friend carers, and the bigger world we all share
- **Integrity always** – we are transparent, act ethically, own when things don't go to plan and do what we say we will
- **Quality every time** – we don't accept 'good enough' because carers deserve our very best every time
- **Speed that matters** – we are agile and don't put off what can be done today.

These values represent how we engage with and serve carers, how we work with each other, and our commitment to the broader community. Carers Tasmania encourages partnership with governments and health and community sectors to enhance service provision and improve conditions for family or friend carers through policy development, research and advocacy.

We acknowledge and support people of all genders, sexualities, cultural beliefs, and abilities and understand that carers in Tasmania, whilst sharing the common theme of caring for a family member or friend, are diverse individuals with varying beliefs, experiences, and identities. We value and respect the diversity of carers, their lived and living experiences, and recognise that carers are the experts in their own lives.

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1. Background

Carers Tasmania is the Peak Body representing the more than 80,000 informal carers within the state.

A carer is a person who provides unpaid care and support to a family member, or friend, with disability, mental ill health, a chronic or life-limiting condition, alcohol or other drug dependence, or who is frail or aged. Informal kinship carers who care for a child under the age of 18, because the parent is unable to, are also recognised as carers. Carers are predominantly family members, but may also be friends, neighbours, or colleagues. Informal carers are not to be confused with paid support workers who are often called 'carers', with the difference being that support workers are fully employed and remunerated with all the benefits of employment. On the contrary, informal carers perform their caring duties without remuneration, other than minimal carer payments and allowances from the Australian Government.

In addition to representing carers through the Peak Body activities, Carers Tasmania provides support to carers living in Tasmania through its service delivery arm, Care2Serve. The Commonwealth Carer Gateway program is delivered through Care2Serve in Tasmania, as are other supports and services, such as the Tasmanian Government's Home and Community Care program.

The Carer Gateway program provides a range of services and supports for carers which are designed to build resilience, increase wellbeing, improve quality of life, and sustain carers to effectively continue their caring roles. The available supports include the provision of information, advice and referrals, holistic identification of carer strengths and needs through a carer support planning process, professional counselling, peer support, and coaching which aims to support carers in achieving specific goals.

Care2Serve, through the Carer Gateway, has capacity to fund certain instances of planned, practical support services such as in-home respite, personal care, domestic assistance, and meal preparation. Care2Serve may also fund items such as laptops to assist carers who are studying or trying to enter the workforce. Care2Serve also coordinates the provision of emergency support during instances where a carer may be unable to provide the care that they usually do, resulting from unexpected illness or injury of the carer.

2. Introduction

Carers Tasmania welcomes the opportunity to provide feedback on the co-design of the new Mental Health Lived Experience Family/Carer/Kin Peak Body (the Peak). We broadly support its development and commend the Australian Government on its “*dedication to ensuring diverse consumer and carer voices are central to, and actively involved in, mental health reform and decision-making processes moving forward.*”¹ It is pleasing that this initiative aims to recognise and value the experience of carers within the mental health space.

We strongly encourage further and extensive consideration, consultation, and planning to occur during the development phase of this important initiative. A carer-centred approach must be taken throughout all stages of development and implementation for this to be a purposeful and sustainable peak. We have not specifically addressed all items posed in the online consultation survey, rather we have outlined our feedback and ideas more broadly based on some aspects of the questions.

We note that Carers Australia, the National Peak Body that represents and advocates for Australia’s 2.65 million carers, has provided a response to this consultation, as have several members of the state and territory carer peak bodies who form part of the National Carer Network. We support and encourage the consideration of feedback provided by Carers Australia and representatives of the National Carer Network.

3. Response to the consultation questions

Carers supporting someone with mental ill health often have different needs and experiences when compared with other carers. This can be explained by the sometimes-complex characteristics of various mental health conditions,² the episodic or unpredictable nature of mental illness, and a lack of education and understanding that often results in stigma and judgement. The responsibilities and support provided by carers in these circumstances may be different from that of other carers and are often more centred around social and emotional regulation and support, keeping the person safe, and supporting them to manage their behaviours.³

Whilst it is important that needs and experiences specific to carers of someone experiencing mental ill health are heard and understood, carers often experience ‘siloes’ approaches to service delivery and a lack of collaboration between different service types. We acknowledge that there are already organisations across Australia providing both national and localised peak body support for carers. Some of these peak bodies are focused specifically on carers of people experiencing mental ill health, whilst others advocate for the broader group of carers. Many of these peak bodies have significant experience in advocating for positive change and have a robust understanding of the history of policy changes and challenges faced by carers. We strongly encourage consideration of how the new family/carers/kin peak

¹ Australian Government Department of Health and Aged Care. (2023). *Discussion Paper – Mental Health Lived Experience Peak Bodies – Family/Carer/Kin Peak Body*. https://consultations.health.gov.au/mental-health-access-branch/nationalmentalhealthlivedexperiencecarerpeak/supporting_documents/Discussion%20Paper%20%20Mental%20Health%20Lived%20Experience%20Peak%20Bodies%20%20Family%20Carer%20Kin%20Peak%20Body.pdf

² Australian Government Productivity Commission. (2020). *Mental Health Inquiry Report. Volume Three*. <https://www.pc.gov.au/inquiries/completed/mental-health/report/mental-health-volume3.pdf>

³ Carers Victoria. (2013). *Invisible Care: Access to Carer Payment and Carer Allowance by Victorian Carers of a Person with a Mental Illness*. Second edition. Melbourne.

body will draw upon this collective knowledge and work alongside existing peak bodies, policy, and advocacy groups for a strong and united approach to supporting carers.

The importance of collaborating with broader, pre-existing carer peak bodies is highlighted through statistics such as those published by the Australian Bureau of Statistics (ABS) in 2018, which showed that of the estimated 2.65 million carers across Australia, approximately 37% were caring for someone experiencing mental ill health. From this group of carers, 43% indicated that mental illness was the primary condition of the person being supported, but for the remaining 57%, mental illness was a secondary, co-occurring illness.⁴ So, whilst there is certainly a need for the development of a separate mental health peak body for family/carers/kin, it is equally important to ensure that other caring circumstances are considered alongside mental ill health. This can be achieved by a commitment to close collaboration with pre-existing peaks to ensure that a diverse range of experiences are considered and valued. This collaborative approach will also strengthen advocacy aims to impact positive change.

From the literature available, there doesn't appear to be a clearly defined purpose specified for this new peak body. To assist in determining the optimum membership, a clear purpose, and Terms of Reference (ToR) must be established. It is unclear whether the group will focus on advocating for issues raised by carers regarding support for those they care for, or if the advocacy should be focused on improving support and service provision for carers, for example, advocating for improved economic security, respite, and carer wellbeing.

In most cases, when carers are provided the opportunity to discuss their needs, they tend to discuss issues regarding access to and provision of support for the people they care for. The *Productivity Commission Mental Health Inquiry Report* from 2020, which is a background paper supporting the development of the new peak bodies, states that “*participation of the consumer’s family or carer actively sought to add to the value and effectiveness of the clinical or support service.*”⁵ Whilst this is undoubtedly true, discussion about reform and change of support and services for those being cared for would best occur within the new mental health lived experience consumer peak body as opposed to the family/carers/kin peak body.

In addition, as separating the needs of carers from those being cared for is often complex, or sometimes not even possible, embedded within the ToR should be a formal mechanism to ensure that the two peak bodies work together where appropriate to ensure a consistent approach is taken on relevant advocacy aims. Often achieving positive outcomes for people with lived experience of mental ill health will have positive impacts on their carers.

We agree that the membership must primarily consist of carers, however, to effectively influence change at policy and service levels, membership of the peak body must also include people who understand how government works. Within the board and operational management of the peak, there must be a balance between family/carers/kin and those who have specific and appropriate legal, financial, and governance experience. This will ensure that the lived experience expertise of being family/carers/kin is at the centre of decision-making, and the operational responsibility will sit with those who have expertise in those particular areas. This will ensure that family/carers/kin are supported in their roles, without the

⁴ Australian Bureau of Statistics. (2018). ABS (Microdata: Disability, Ageing and Carers, Australia, 2018, Cat. no. 4430.0.30.002).

⁵ Australian Government Productivity Commission. (2020). *Mental Health Inquiry Report. Volume One*. <https://www.pc.gov.au/inquiries/completed/mental-health/report/mental-health-volume1.pdf>

pressure of legal and other responsibilities, and will support the sustainability and operational effectiveness of the peak.

Another important consideration, that will impact the ToR, purpose, and membership structure, is the amount of responsibility and workload that will be required by the family/carer/kin members. Drawing from our experience here in Tasmania, often carers are so busy supporting the person they care for, that their time to participate in consultation, co-design, and governance groups is limited. How and where the group functions will be important, as will be the required commitment by family/carer/kin both inside and outside of meetings. Inclusive awareness raising and support must be provided to assist and encourage family/carer/kin to apply, and there must be a commitment to take a strong focus on upholding and supporting the wellbeing of the family/carer/kin who become members.

The first two sections of the survey address ensuring that the voice of those most affected is reflected within the group and that the leadership of the group is centred on lived experience. We support the aspiration to create an inclusive, diverse, and carer-led peak body, however, due to the challenges that many carers face, particularly those in more marginalised communities and circumstances, the members of the group, whether it be organisational members or actual carers, must be able to create strong and meaningful relationships with other carers in their communities. This will help ensure that the voices and experiences of a diverse range of carers can be included. This is also another reason to ensure that collaboration with pre-existing national and local carer peak bodies occurs.

It is critical for the peak to provide nationwide representation. Even within the same state, there can be significant differences in service access and provision. Carers Australia models a good example of nationwide collaboration. They work on a federated model in collaboration with representatives from each state and territory carer peak body. The state and territory representatives are responsible for engaging with carers across their state or territory and relaying experiences and information back to Carers Australia so that the varying localised experiences can be included. Another example is the National Mental Health Consumer and Carer Forum, which has both a lived experience and a carer member representing each state and territory in Australia.

To avoid duplication of work already being undertaken by current and former carer peak bodies and advocacy groups across Australia, we strongly recommend that the ToR explicitly specifies that the new peak body must work in partnership with pre-existing peak bodies. As many of these peak bodies have been operational for many years, they understand the long-standing policy landscape and changes, already have strong advocacy aims, and even more importantly, have trust and strong relationships with the carers in their communities. The survey provides a list aiming to incorporate a diverse representation of carers within the peak body. We contend that nationwide representation of existing peak bodies is equally as important.

The third section of the survey considers the sustainability of the peak body. It suggests a model whereby an organisation is funded to establish the peak body initially, including preparing the constitution, structure, and organisational processes. These structural and governance mechanisms are important and will assist in developing the ToR and membership of the peak body. It may be appropriate for an existing peak body to establish the new peak body to ensure that an optimal governance model is implemented. The survey states that during these initial stages, collaboration should occur with the lived experience sector and communities. We strongly recommend that carers be involved at this stage as well, for the peak body to be truly 'carer led' as previously outlined. Existing peak bodies

should also be involved in these initial stages to ensure the new peak body builds on existing sector knowledge and experience.

The survey discusses sustaining the financial viability of the peak body and suggests there should be paid membership for some or all members. Further clarity is required about the paid membership, as it is unclear as to whether this is referring to members being remunerated for their time, or members being required to pay for their membership. Carers Tasmania believes that any carers who are participating in a group such as this should be remunerated for their time, efforts, and expertise.

Again, drawing on recent experiences in Tasmania, a Minister's Carer Advisory Council was established this year, which aims to support the Tasmanian Government's understanding and leadership of better-supported carers in Tasmania. This group is led by the Minister for Community Services and includes representatives from various government departments, representatives from relevant carer organisations, and also five people with lived or living caring experience. The ToR for this group currently does not provide remuneration for the carers involved. Throughout the application process for this group, the fact that there was to be no remuneration was an enormous barrier which resulted in many carers not applying.

4. Conclusion

To conclude, we encourage further consultation, consideration, and planning to occur on how to best establish the new Mental Health Lived Experience Family/Carer/Kin Peak Body. This must take a carer-centred focus at all stages. This will ensure that the operational structure, purpose, and functions of the peak will be sustainable, uphold the wellbeing of family/carer/kin members, and importantly assist in collaborative advocacy for meaningful positive change.