

2 November 2023

Response to Discussion Paper - Mental Health Lived Experience Peak Bodies - Family/Carer/Kin Peak Body

Sent via email: LivedExperience@Health.gov.au

Carers Victoria welcomes the opportunity to make this submission in response to the Discussion Paper – Mental Health Lived Experience Peak Bodies – Family/Carer/Kin Peak Body. For the purposes of this response, ‘carers’ will be used as the term to encompass family, carers, kin and supporters.

Carers Victoria is the state-wide voice for unpaid carers in Victoria. It provides a wide range of services and programs to support Victorian carers in their lives and caring roles, including the family, carers, kin and supporters of Victorians living with a mental illness and/or psychological distress.

This submission will focus on our perspectives as a state based peak body: we have also contributed to the Carers Australia submission.

Creating a family/carer/kin peak body that privileges the voices of those most affected and centres mental health lived experience leadership.

Valuing diversity and promoting inclusive approaches to membership and operations

Carers Victoria supports in principle mechanisms that increase the involvement of people with living or lived experience of caring and is keen for those bodies to reflect the diversity of care experiences.

It does however note that any such body needs to be designed in a way that:

- takes into account existing organisations and mechanisms established for similar purposes;
- ensures that those organisations can continue to contribute their diverse perspectives to future policy and programs, as this will provide a greater level of diversity than any single body can¹;
- provides a consistent approach between the design adopted for the proposed consumer peak and that for the carer peak, given both are proposed to be similar in function;

¹ For example, as Carers Victoria works with a diverse range of carers, it brings unique cross-system evidence and insights regarding the mental health needs of carers as well as the needs, priorities and experiences of people caring for people with multiple needs that extend beyond (but include) mental health.

- incorporates young people who have living/lived experience of caring, so that their specific needs, insights and expertise inform and shape the plans which impact their futures, and
- incorporates carers of multiple people with care needs.

Embedding lived experience in leadership and governance structures

In Carers Victoria's experience, for such an entity to be successful it needs to have:

- people with the core skills, knowledge and attributes to effectively lead and govern the organisation, with as many of these as possible also having living/lived experience – if there are reserved positions, it would be wise for these to combine both skills and lived experience;
- a sophisticated understanding of role and boundaries, so both staff and those in governance roles understand the parameters of the role they are playing and how they apply their own living/lived experience within this; and
- appropriate HR practices, governance frameworks and practise models operating that recognise the potential impacts such work can have on people with living/lived experience and ensure their continued safety and wellbeing.

Ensuring the family/carer/kin peak body is sustainable, viable and responsive to evolving needs of diverse lived experience communities

Carers Victoria is supportive of an approach that ensures the long-term financial sustainability of the family/carer/kin peak body. However, it does not support the imposition of a membership fee for family/carers/kin to achieve this.

Caring often impacts on the capacity to participate in paid employment, exacerbating financial pressures in the short and longer term. Survey data confirms lower workforce participation, income levels and economic security in retirement with relatively small numbers of carers qualifying for government assistance in their caring role and high levels of financial pressure.

For example, only 10% of Victoria's carers receive the Carer Payment, and survey data found 1 in 2 carers experiencing financial stress and 1 in 7 experiencing financial distress. In this context, even a token membership fee may still be too much for a carer and thus pose a barrier to participation.

Creating opportunities for the two peak bodies to work together, while recognising the distinct voices, needs and experiences of mental health consumers and of families, carers and kin

Carers Victoria supports this approach in principle noting that it is similar to recommendations made by the Royal Commission into Victoria's mental health system. Here, it was recommended people with lived experience of mental illness or psychological distress and families, carers and supporters be recognised as two distinct groups with different perspectives and experiences. Following this, engagement methods were to be designed to account for varied perspectives and experiences and create opportunities for groups to come together.

As many carers may be supporting people who have mental health conditions (but not as their primary presenting condition) and/or may have their own mental health challenges, it will be especially important to design specific engagement mechanisms for these carers.

We look forward to hearing the outcomes of this stage of the consultation process and are happy to assist the Department if/as desired. Should you wish to discuss any of this content or issues arising, please contact Dr Margaret Boulos, Senior Research and Policy Advisor on margaret.boulos@carersvictoria.org.au or 03 9248 9610.

Yours faithfully,

A handwritten signature in black ink, appearing to be 'JA' or similar initials, followed by a horizontal line.

Judith Abbott
Chief Executive Officer
Carers Victoria