

SUBMISSION

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

Submission Title:	Mental Health Lived Experience Peak Bodies – Family/Carer/Kin Peak Body
Date:	Thursday 26 October 2023
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CARERS QUEENSLAND

The activity and impact of providing care is best understood in terms of its context; as a relationship between two or more individuals, rooted in family, friendship, or community. Caring is a role rarely chosen by most, nor does it discriminate. Children and young people, people of working age and older people, people with disability, people who identify as culturally and linguistically diverse, First Nations Australians, people with diverse bodies, genders, relationships, and sexualities and those living in rural and remote Queensland provide care to family members or friends daily. For some caring is a short-term commitment whilst for others, it is a role that literally lasts a lifetime.

Family and friend carers provide unpaid care and support to family members and friends who have a disability, mental illness, chronic medical condition, terminal illness or are frail aged. Carers come from all walks of life.

Carers Queensland is the peak body representing the diverse concerns, needs and interests of caring families in Queensland. Carers Queensland believes that all carers regardless of their age, disability, gender or gender expression, sexual orientation, religion, socioeconomic status, geographical location, or their cultural and linguistic differences should have the same rights, choices and opportunities and be able to enjoy optimum health, social and economic wellbeing and participate in family and community life, employment, and education like other citizens. Carers Queensland's mission is to improve the quality of life of all carers throughout Queensland.

We aspire to provide an independent platform from which to advance the issues and concerns of the 533,200 carers in Queensland and believe our knowledge and expertise in carer issues means we can provide the Government with relevant and trusted information that will ensure that the needs of carers will be recognised, respected, and acted on.

Our submission is informed by national and international peer reviewed data, our own experience as a service provider and the personal and often difficult admissions of carers, those people who provide unpaid care and support.

Introduction

Family and friends who provide care and support to loved ones experiencing mental ill health and fulfil a vital and irreplaceable role within society, often at the immediate and longer-term expense of their own health, psychological, physical, and mental health, and economic needs, which are frequently are overlooked or dismissed. It is essential that this cohort receives robust, evidence-based systemic advocacy, supported by an awareness campaign, and culturally safe and trauma-informed support.

Carers Queensland believes in the need to establish a peak body to represent the needs of those providing care and support to loved ones experiencing short or long term mental ill health.

Discussion

While knowledge, evidence and research have advanced medical and societal understanding of mental health, there remains a significant stigma surrounding mental illness, the individual and their families, some of which has been perpetrated by the medical profession who continue to attribute some blame to the family (traditional and non-traditional) for the presence of poor mental health in an individual.

For example, one carer recently advised us that she has frequently felt blamed by medical professionals when attending medical appointment for her child with mental ill health, she has been subject to intrusive and irrelevant questions about problems at home.

This stigmatisation has resulted in social marginalisation. In consultations with carers, we have heard recounts of carers of other population groups feeling ‘pushed out’ of the carer space by mental health carers. It is for these reasons that we support the establishment and existence of a national lived experience peak body for mental health carers, families, and kin.

Carers Queensland believes the new national peak body for mental health carers, has a responsibility to represent and include the entire spectrum of mental health in their membership and systemic advocacy activities. It is essential the peak body represents carers and families who provide care and support to:

- Individuals with short and long term mental ill health
- Individuals impacted by trauma, and any trauma based disorder
- Individuals affected by alcohol and substance abuse and/or any other form of addiction
- Individuals affected by actual or threatened suicide
- Individuals with a dual diagnosis
- Multiple individuals within the same household with mental ill health or other disability

It is important to recognise the complexity experienced by many carers who provide care and support to more than one individual with mental ill health or who have a dual diagnosis of mental ill health and other disability. For many families, mental ill health is not an isolated diagnosis, and it is important the national peak body recognises, understands and is able to adequately represent the broad spectrum of carers and families in these circumstances. We also believe the issue of young carers and children within families who provide care and support must be recognised with specific work done by the peak to raise awareness and provide advocacy and support for these children and families.

Lived experience is essential in any sector working to the betterment of a specific cohort within the Australian population. Leadership lived experience in the proposed national peak body requires

consideration. It is the opinion of Carers Queensland, that where possible, lived experience in the leadership and governance of the national peak would be essential, it is important that the leadership of the organisation has the necessary skills, qualifications, and experience to be able to ensure this peak body is as successful and effective as possible. Carers Queensland would like to propose identified lived experience positions to be created in the leadership and governance within this newly formed peak organisation. Representation is essential because it provides validity to its intended membership.

The primary function of this proposed national peak body for carers, family, and kin, is, in our opinion, to provide evidence-based systemic advocacy for carers, families and kin, to improve awareness of and raise the issues experience and promulgate the rights of carers, families and kin. Mental health attracts institutionalised stigma, misunderstanding and discrimination within society, as a result of this carers in this sector feel isolated, unrecognised, and often have no viable options of support, particularly when the mental health of the individual does not meet disability eligibility requirements. Additionally, within mental health supports and services, carers and families have no rights to participate in medical appointments nor entitled to any information about treatment or expected outcomes. However, carers are expected by mental health practitioners to monitor the daily mental health of the individual and assist when appropriate with treatment options and to tolerate and deal with behavioural changes.

The National Carer Network is a pre-existing network comprising representatives from the carer sector from every state and territory within Australia. It is the belief of Carers Queensland that the new national peak body for mental health for carers, families and kin should work in partnership with the established National Carer Network. The current network has a wealth of historical and relevant knowledge and information about this sector, which would be beneficial for the success of both groups to work together. Mental health carers, while facing unique challenges, do have similarities with carers from other cohort populations, and where possible both national bodies should have a clear agreement of how they can work together for more success and greater achievement. Furthermore, there are a number of organisations which support particular population groups, who are at a statistically higher risk of developing mental ill health. These population groups include LGBTQ communities, First Nations Peoples, refugees, culturally and linguistically diverse and emergency service workers. It is essential the proposed peak body is able to work in tandem with these organisations to ensure their work is evidence based, culturally safe and required, and works with these organisations to the betterment of carers, families, and kin within these population groups.

Carers Queensland would like to propose the following issues for consideration, that we believe the new national peak body will need to be able to:

- It represents the needs of every mental health carer, family and kin across Australia, including those in rural, remote and offshore areas.
- It has a specific strategy for representing the needs of children living within families affected by mental ill health.
- Led by trauma informed policies and embedded practices, ensuring the risk of re-traumatisation for those with lived experience is low
- Have clearly developed corporate governance structures and practices in place outlining the role, responsibilities, and structure of the organisation – including how it will work and manage potential conflicts of interest with the mental health consumer peak body and the national carer network

- Have defined and well researched systemic advocacy priorities with measurable outcomes

Recommendations

Carers Queensland makes the following recommendations:

- The membership of the proposed peak body needs to represent the spectrum of mental health carers, families and kin – not just the well-known and socially acceptable disorders
- Lived experience to be included in the leadership and governance of the peak body, balanced against qualifications, skills and experience
- A documented agreement in how the peak body will work in partnership and alignment with the existing national carer network.
- To be trauma informed and ensure operational practice is derived from best practice with an understanding of the role of trauma and clear measure in place to reduce the risk of re-traumatisation
- Develop a mental health carer, family and kin strategy with defined measurable outcomes.