

Carers ACT – Mental Health Carers Voice

Introduction

Carers ACT is funded to provide services as the Peak Body for mental health carers in the ACT. This activity undertaken by the Mental Health Carers Voice Program (MHCV).

The aims of the MHCV are to;

- To build carer capacity, confidence and wellbeing through the provision of accessible and relevant education, information, support, counselling and referral for mental health carers
- That carers are identified by services they engage with and are appropriately supported in their caring role, avoid crisis and improve their personal wellbeing
- That the carer voice is heard and achieves positive systemic change through building carer confidence and participation in systemic advocacy
- To promote mental health carers needs to ACT government, ACT Health through the provision of informed evidence based policy advice that is purposeful and proactive

The MHCV has therefore designed various activities that shall progress towards these objectives which include;

- Educational Programs such as Keeping Families Connected, Psychoeducation and MH Service Navigation
- Providing up-to date information to carers through the development of resources and working to upskill staff interacting with mental health carers in the sector.
- Support groups, events that support carer health and wellbeing
- Provide training to mental health sector including ACT MHJHADS staff regarding working with carers
- Keeping carers up-to date regarding changes to the sector and provide opportunities to voice their needs and expertise
- Seeking out carer input from a broad range of mental health carers on key areas of need or current changes
- Provide training to carers in participating in advocacy and encourage active participation
- Develop policy papers including position statements, submissions, media releases, responses etc. that are informed by carers views and experiences.
- And more;

Within the ACT, the mental health sector is undergoing rapid changes to how mental health services are funded, delivered and overseen. This includes the changes in mental health responsibilities of our Primary Health Network – Capital Health Network, the service changes in the ACT Health MHJHADS, the full roll-out of the National Disability Insurance Scheme and the ongoing impacts to community mental health, the appointment of Minister Shane Rattenbury as Minister for Mental Health as well as the announcement of the development of the ACT Office for Mental Health

This has added complexity for many carers in attempting to navigate the system personally as well as understanding their role in advocating for change. As a result, it seemed timely that as a program we revisit our core purpose and determine what the role of the peak body for mental health carers in the ACT looks like moving forward. This paper specifically examines the carer engagement aspects of the MHCV and should be read in the context of the full Mental Health Carer Capacity Building Program Design.

Observations of carer engagement

In developing this document, it comes not only in response to external systemic change but also, in many ways to carer feedback regarding their experiences of engagement. In our program design previously, there was a strong focus on Mental Health Carer Representation on committees and working groups. This has been the standard for good consumer and carer engagement for many years and followed the partnering with consumers rhetoric of the *'Nothing about us, without us'*.

Many carer representatives involved in systemic advocacy felt that the role was highly important because being present in the room put carers needs in the forefront of peoples' minds. We also had people who had been mental health carers for a long time and really wanted to give some of their expertise to improve outcomes for future carers.

However, there were also hurdles in carer representation being the primary model for engagement. For many carers sitting on a committee was unappealing, intimidating and/or impractical. Even with training and support carers had experiences of the committee work being very slow, feeling unheard or 'out of the loop' and unsure of how they contributed. It was also mentioned that it felt prohibitive to many carers as their working role or their caring role made it difficult to commit to regular engagement with the committees.

We also received specific feedback from Aboriginal and Torres Strait Islander carers, Culturally and Linguistically Diverse carers and Young Carers that that model for carer engagement felt very exclusive and intimidating with elevated levels of bureaucratic processes that they did not understand and the use of jargon making it feel like they did not belong. We attempted to alleviate this by having focus groups with these carer cohorts to feedback to the carer representatives on the committees these other carer views, but carer representatives reported that the opportunities to contribute feedback such as this was limited by time and whether the comments were deemed relevant or were 'parked' within the meeting.

Because of these difficulties, carers who were interested and able to participate in carer representation were often similar in their background. They had been caring for many years, the person they cared for was generally more stable in their mental health or had passed away. They were predominately composed of white-Australian, retired public servants with a slight over representation of males (when considering most primary carers are female). Many of these carers have also been involved as representatives beyond their recommended term because no other carers have approached to nominate, which added stress and strain to these carers because they felt a duty to continue the work they do.

However, considering the many changes the sector has undertaken, many of these carers have not engaged with the current services or under the current legislation. This has meant that we have increased need to provide the carer representatives with more insight into other current carer experiences of services to keep their representation relevant. Due to the slow nature of systemic advocacy as well, many of our carer representatives are feeling disenchanted by the hope of improving mental health services. Especially recently, carers involved in the design of the ACT Mental Health Act 2015 have been disappointed by its implementation and still await the cultural change of carer inclusion.

Our observations of carer engagement have been largely positive, however there are clear difficulties in sustaining this model moving forward. From our experiences it is a necessary component but should not be the principal component to good carer engagement. With so many different areas of change there is a need to define our methods for carer engagement and develop clear decision making regarding priorities based on carer need. This will hopefully involve capturing a broad range of carer experiences, across the many changing areas of mental health, maintaining carer wellbeing in this unstable environment and ensuring that the information is purposeful and producing good outcomes for carers

Methods for Carer Engagement – Moving Forward

In developing this framework, our aim is to ensure that we obtain improved breadth and depth of mental health carer engagement. As such, we believe that it is important to have a multi-modal approach to ensure that a broad range of carers can input at differing levels. This means that there will be a move away from a representative-centric model to a model with multiple means for participation.

Our primary tier of engagement would be aimed at engaging all mental health carers in the ACT and would consist of opportunities such as;

- Focus groups
- Deliberative Processes
- Research Participation
- Surveys and Polls
- Workshops
- Carer stories

Our secondary tier of engagement would be for carers seeking to be more actively involved and would include;

- Position statement feedback
- Policy submission feedback
- Carer representation
- Media and Public Speaking
- Development of resources for carers
- Research collaboration

Our primary tier would feed into the work undertaken in the secondary tier and the combination would ensure the authentic carer's voice representation throughout the program.

This framework is constructed to value carers' time and expertise. The intent of the design is that more methods and therefore more carer input will be sought for issues that are likely to have the greatest impact on mental health carers. It is also intended to enable more proactive work to be undertaken in addition to responding to opportunities as they present, within the sector.

With a greater push in the sector to be consultative, we have witnessed the impacts on carers of 'consultation fatigue' whereby carers feel that they have been asked their opinion on an issue many times and witnessed minimal change. This can have many negative impacts on carers whereby they become disenfranchised with being consulted, feel it is tokenistic, a waste of time and that they are powerless in the system. This has negative impacts on carers mental wellbeing and has the opposing outcome from that intended, whereby carers became less engaged in the conversation. This model aims to address that by proactively seeking carers views on services and topics that arise regularly and then utilising that feedback to advocate for carers needs.

In this way proactive work shall be an investment into responsive work to reduce the amount of demand for input from mental health carers on the same issues and reduce duplication. This shall also assist with ensuring good follow up is prioritised from previous consultations so that carers are made aware of the positive impact their input has had. It also addresses some of the barriers to engagement identified in the previous section where carers will be able to participate in a manner that acknowledges their caring role and capacity.

Decision making framework for selecting method and priorities

The most meaningful change for this program will be within its governance framework. As a cohort, mental health carers are experiencing change and requests for input into a vast amount of sector reform. This includes, but is not limited to, inpatient mental health, primary mental health, carer supports, community mental health, disability, housing, education, welfare payments and more. As a result, and as stated above, there is a need to prioritise the issues and to utilise carers time and expertise on the issues that are most likely to have direct impact on mental health carers.

To undertake this, it is proposed that two carer-led approaches are utilised for decision making regarding the priorities for carer engagement and the methods utilised for each priority.

Firstly, the establishment of an annual mental health carer survey for identifying priority issues and secondly a Mental Health Carers Voice Committee that would be responsible for distilling the survey results into an annual engagement strategy.

The Mental Health Carers Voice Committee would be comprised of ACT mental health carers and be advised by the Mental Health Policy Officer at Carers ACT. They would retain ultimate responsibility for the direction of the program. More detail regarding the committee Terms of Reference, Code of Conduct, Application Process etc. will be provided in supporting documentation. All members of the committee would be responsible for adhering to their role responsibilities and would be paid an honorarium from Mental Health Carers Voice for their involvement. The Committee would both decide on the priority areas for focus at the start of the year and then as opportunities arose for carer involvement, would identify whether it aligned with the priorities and if so, the level of carer engagement it merited.

A potential future scenario:

Many carers comment in the annual survey that it was very difficult when the person they cared for was discharged from hospital and felt that they needed more information and assistance.

This was taken to the committee and the committee agreed this was a key priority area. They also decided that it was an area likely to have a high impact on carers. Therefore, they put into their Annual Engagement Strategy that the MHCV program should utilise multiple carer engagement strategies. They chose to undertake a large survey on the issue, run some focus groups with mental health carers and undertake some key stakeholder workshops to identify the carer experiences, barriers for staff and potential enablers for greater engagement. They then requested the Mental Health Policy Officer to write a recommendations paper based upon this for them to endorse.

Then depending on the response and the recommendations made, the committee could feedback to carers the outcome of the work ie. agreement or otherwise to implement recommendations.

As part of this, it was requested by ACT Health that a carer representative becomes involved in an ACT Health MHJHADS committee implementing the recommendations. The MHCV Committee would assess the necessity and capacity of this and either appoint a carer representative, appoint the Mental Health Policy Officer or chose to receive meeting papers from the committee to keep abreast of progress.

It would also be listed as an item to follow up in the following years annual survey.

After this work had been undertaken, it was identified by Capital Health Network that they would be undertaking a project to find out how best GPs could support people with mental illness following a hospital admission. CHN requested advice from MHCV Committee who decided it aligned with the priority identified, however that the recommendations paper previously written would provide the key information from carers views. It was sent to CHN and CHN were asked to keep The Committee informed of progress.

Putting the Carer First

A central principal for this carer led framework to be successful is a commitment from carers to think about their own needs. It is often difficult in the carer advocacy space for carers to identify their needs as separate to the needs of the person they care for. For families, the needs are too entwined to separate, and many carers consider their advocacy role to sit as acting to advocate for more mental health services for the person they care for.

Whilst this is undeniably a major issue within mental health advocacy and the MHCV continues to promote the enormous need for greater investment in all levels of mental health to ensure the right treatment is available at the right time. This is advocacy that is taking place through most, if not all, the mental health peaks and we would have little new to add to that conversation.

Therefore, part of the decision making and the program direction needs to be about being non-duplicative, partnering with other peaks where it is best for an advocacy position and also solidifying our role as **Peak Body for Mental Health Carers in the ACT**.

This framework, therefore, identifies that focus for advocacy work needs to meet the following criteria;

- Does the issue have a significant impact on mental health carers? What is that impact?
- Is this an issue specific to the ACT or one where the ACT is uniquely positioned to comment?
- Is this an issue where carers and consumers may have different views?
- Is there any other significant work being undertaken that we should participate and collaborate on instead?
- What is the likely outcome for undertaking this activity and is the timing right?

It will be the responsibility of the Mental Health Policy Officer to provide this advice throughout the year to the MHCV Committee to incorporate into their decision making.