

CARER REPRESENTATION TERMS OF REFERENCE

1. Introduction

1.1 Carers ACT supports mental health carer representatives to participate at all levels of policy and service development. The involvement of mental health carers in issues that affect their lives is fundamental to progressing mental health carer support and service options.

1.2 It is essential that this representation is positive, influential and representative of the diversity of the mental health carer population. Carers ACT believes that mental health carers need and deserve support to take up this role through the Mental Health Carers Voice program. The experience needs to be constructive and productive both for the mental health carer representative, the committee, and for Carers ACT.

1.3 Mental health carer representatives recognise that their membership is for, and on behalf of, mental health carers as a whole and, as such, will seek to share information with, and obtain feedback from, other mental health carers wherever possible.

2. Roles and Responsibilities

2.1 Carers ACT and mental health carer representatives participate in this program in accordance with the roles and responsibilities set out in **Attachment A** to this document.

3. Purpose of Mental Health Carers Voice, the Carers ACT Mental Health Carers Representation Program

3.1 Mental Health Carers Voice supports mental health carers to have a voice in influencing mental health services in the ACT with a view to improving the level of carer satisfaction with those services.

3.2 Whilst mental health consumers and carers have many needs and concerns in common, they also have very distinct and separate needs.

3.3 All public, private and non-government organisations should recognise the distinction between consumer and carer issues and needs. It is generally considered inappropriate for consumers to represent the interests of carers, and for carers to represent the interests of consumers. However, Carers ACT recognises that in some specific circumstances carers may be appropriate advocates on the consumer's behalf, depending on the level/aspect of representation. Moreover, in some circumstances there can be a substantial overlap between consumer and carer roles.

3.4 Mental health carers have been, and will continue to be, strong advocates for better health and community services for their relatives and friends. Wherever appropriate, both consumers and carers should be active: i.e. that carers are current in their caring role, as defined by being a carer who is currently caring for their family member or friend with a mental illness, or whose family member or friend is no longer in their care for any reason (due to death, change in living arrangements, moving, etc) but who has been a current carer within the last 5 years.

3.5 Mental health carers provide unique expertise due to their lived experience of caring. Furthermore, carers are directly impacted upon by the quality and effectiveness of health and community care and, therefore, should be considered key stakeholders.

3.6 Mental health carer representation in determining health and community care priorities ensures a sound basis for successful processes, programs and services to maintain and improve care for all Australians. Mental health carer representation can assist policy makers and service providers to provide services in a manner that is relevant, sensitive and responsive to carers.

3.7 Carers ACT believes that representation is fundamental to the rights of all carers.

3.8 Carers ACT believes that mental health carer representation should be promoted at all levels of health and community care. It is our goal to encourage health and community services to operate with a genuine commitment to optimising carer representation and to valuing their contribution. In principle, mental health carer representatives will only be nominated to undertake representation on one committee or working group at any one time.

4. Feedback and Evaluation

4.1 The Carers ACT Board of Directors will ensure that evaluation and review of the Mental Health Carers Voice policy and process of mental health carer representation will occur annually. Following the review process, policies and practices will be changed to reflect the outcomes of the evaluation. In addition, in order to facilitate the evaluation of mental health carer representatives, Carers ACT will request from external committees guidelines for formal feedback on all carer representatives provided by the Mental Health Carers Voice program.

4.2 Conflict and other feedback will be dealt with in accordance with the Grievance Process as documented and included in the program information pack provided to all members.

ATTACHMENT A

Roles and Responsibilities

The Role and Responsibilities of Representatives

A mental health carer representative is a committee member or educator who voices the mental health carer perspective and takes part in the decision making process *on behalf of carers*. This person is usually nominated by, and is accountable to, an organisation of carers. In the ACT, this organisation is the mental health carers' peak body, Carers ACT.

The role of a carer representative is to represent the needs and concerns of mental health carers from the ACT across a variety of health and community services forums at local and federal levels.

As representatives of the Mental Health Carers' Voice program, carers have the right to:

- feel safe and to participate freely in their role,
- training to maximise their contribution,
- be appropriately briefed about their role and function on a committee,
- be appropriately remunerated for their contribution,
- acknowledgment of their ideas and work, and
- identify practices and attitudes that are inappropriate and bring those practices or attitudes to the attention of Carers ACT.

As Mental Health Carers Voice program representatives, carers have the responsibility to:

- actively contribute and participate in committees/forums where they are representing the perspective of mental health carers from the ACT
- undertake appropriate preparation work, including preparation that includes engaging with other mental health carers across the ACT to glean their perspectives
- consult with Carers ACT and comply with **all** reporting mechanisms, both verbal and written, to ensure transparency and clarity in their representation and to ensure that Carers ACT and ACT mental health carers are kept well informed
- respect the confidentiality of proceedings of meetings
- participate in activities with the broader mental health carer constituency, designed to ensure that carer representatives understand the perspective of all mental health carers.

Representatives are expected to attend training as required.

The Role and Responsibilities of Carers ACT

Carers ACT requires that Terms of Reference and any other relevant documentation are made available to all interested carers prior to nomination on new committees. This will ensure clarity and transparency in the roles and responsibilities of all such representative positions.

Carers ACT will have appropriate processes in place in the event that carer representatives are unable to attend committee meetings. Where appropriate two mental health carer representatives could be appointed to a committee to provide peer support and cover for ill health or other eventualities.

Carers ACT has a Code of Conduct in place for the Mental Health Carers Voice program. All mental health carer representatives are to be provided with a copy of the Code of Conduct.

The selection process for carer representatives will be transparent and will ensure nominations are sought appropriate to the level of representation required.

In engaging mental health carers, Carers ACT will seek representatives with appropriate expertise and access to the constituency they represent. For example, that expertise and constituency may relate to the particular illness, life stage or to special needs groups (*e.g. Aboriginal, non-English speaking background, Young Carers*). In instances where there are no representatives with the desired level of expertise, Carers ACT will put in place processes and partnerships that will nurture and support the development of informed, skilled and confident mental health carers.

Carers ACT will maintain a database of mental health carers who have given consent and are available for representation, as well as a list of other carer groups/organisations who could provide mental health carer representatives. Such a database will ensure a broad network of mental health carers who are easily contactable and readily available to represent given timely information and briefing. Where appropriate, the database can distinguish between mental health carers preferring only local level representation and those with expertise to undertake broader representation.

Carers ACT requires that health and community organisations seeking a carer representative should provide sufficient information. This information should include the purpose, composition, remuneration and time commitment required for the committee or consultation, to enable Carers ACT to canvass suitable mental health carer representatives.

Carers ACT will endeavour to ensure mental health carer representatives are provided with all relevant information necessary to their representation activity in a timely manner. This will provide carers with time to read and become familiar with the meeting documents, as well as provide time for representatives to consult with Carers ACT.

Carers ACT will ensure that information flows between the organisation and mental health carers as required by both the organisation and the carer/s.

Mental health carers should not be required to bear representation expenses. Carers will receive payment for their representation and reimbursement of reasonable expenses incurred during their recognised representation work. In principle, these expenses are covered by a sitting fee. In situations where these expenses are considerable it is preferable for the organisation to provide vouchers, be directly invoiced or pay the expense up-front rather than make reimbursement. Payment conditions will be established upfront wherever possible with remuneration equivalent to the rates and conditions set for fellow participants. Should funding be insufficient to meet these costs, rates for mental health carer representation should be negotiated with Carers ACT.

Carers ACT will provide ongoing support, information, education and training for mental health carer representatives appropriate to the level of representation they are engaged or interested in. The type of information, support and education needed may vary greatly according to whether the carer representative is participating in activities on a local or national level, and on the nature of the actual activity *eg participating in a local working committee, in a national advisory committee, a one-off issue consultation, a conference presentation or professional education.*

The mental health carer representative should be provided with those resources reasonably expected in order to perform their duties. Primarily, this would be provided by prior arrangement at the Carers ACT premises in Holt during business hours.