



## **Consumer Participation and Carer Participation across Mental Health ACT**

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# **A FRAMEWORK FOR ACTION**

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*Response to Come to the table: discussion paper*

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## Foreword from the Minister for Health

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*Consumer Participation and Carer Participation Across Mental Health ACT: A Framework for Action*, is an important milestone towards the genuine inclusion of consumers and carers in the development of mental health services in the ACT.

The *Framework* gives recognition to the significance of partnerships and open dialogue between the government and the community it serves. It acknowledges the rights of consumers and carers to participate in the decision-making process, a process that informs and shapes the activity of government.

The relevance and value of consumer and carer participation in decision-making across all levels of mental health services has been increasingly recognised nationally over the past decade.

In 2006, Mental Health ACT progressed this ideological shift and undertook a project to develop a framework for consumer and carer participation across the organisation. The *Framework* is the product of extensive consultations held in the community, which included mental health consumers, carers and other relevant stakeholders.

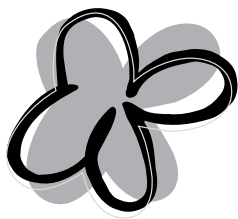
The *Framework* consists of two parts; capacity building within Mental Health ACT and the community, and secondly, a range of strategies for participation. The information gathered has shaped and informed the *Framework's* final principles of participation and will further influence and consolidate the engagement and involvement of consumers and carers in the organisation's future directions.

The *Framework* is further demonstration of the ACT Governments ongoing commitment to genuine and long term partnerships with mental health consumers and carers. It promotes the importance of real conversations and true engagement of all parties across all levels of the organisation, as a means of shifting the boundary lines that can restrict change and defer new beginnings.

This innovative *Framework* extends an exciting challenge to Mental Health ACT, consumers and carers, to further consolidate the quality of participation already in place.

A handwritten signature in black ink that reads "Katy Gallagher". The signature is written in a cursive, flowing style.

Katy Gallagher MLA  
Minister for Health



ACT  
Mental Health  
Consumer Network

## Foreword from the ACT Mental Health Consumer Network

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The document you are about to read is an exercise in vision, word and practice. It has come about as a consequence of a vision of a future where the people who are most directly affected by mental health services – consumers and carers – are also the people who most influence service development, implementation and evaluation. In the process leading to this document this vision has been reshaped into words and the document itself is a marrying of those words with the limitations of practice – of what is realistically attainable and how it can be achieved in practice. Like any document trying to marry vision with practice “Consumer Participation and Carer Participation Across Mental Health ACT: A Framework for Action” is an imperfect document – a compromise. We should not, however, let that stop us from recognising the very real progress that this document signifies and the potential flowing from it.

The ACT Mental Health Consumer Network devoted a great deal of resources to participating in the process of developing the Framework. The Network aimed to make it a central understanding

in the Framework that we, the consumers, are the community, we are the end users of mental health services and, as we are those most directly affected, we should have ownership of these services. For consumers the Framework thus primarily represents a formal acknowledgement of the role of consumers and carers at all levels of decision-making in Mental Health ACT.

Participation is widely valued as a tool to improve quality and ensure accountability – ensuring that services are appropriate, accessible and responsive – and an important democratic right. In addition research shows that the process of participation is in itself an aid in improving health outcomes. Looking to other states and territories there is a growing recognition not only of the benefits of consumer and carer participation in health services, but also of the need for a firm commitment to the participation process within health services and for leadership from above, if participation is to be genuine and successful. The Framework is a sign that such a commitment exists within ACT Health. With the Framework as a starting point we can now move towards a genuine partnership between consumers, carers and mental health services in the ACT.

ACT Mental Health Consumer Network

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# Executive Summary

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## Background

Consumers and carers have a right to participate in decision-making about mental health services they have accessed or would like to access. This is reflected in the number of opportunities now available for consumers and carers to participate across Mental Health ACT, for example on committees, employment of consumer consultants and in provision of staff education. In response to a review of clinical services of Mental Health ACT, recommendations from consumer consultants and feedback received from other consumers and from carers, Mental Health ACT agreed to review current procedures and develop a framework for future development of participation across the organisation.

## The Participation Project

A project officer worked with consumers and carers to develop a discussion paper *Come to the table: a discussion paper*. The paper offered a proposed model for participation of consumers and carers across Mental Health ACT. The paper was widely advertised for public comment and feedback was received by various avenues, for example, focus groups, a phone-in and email. The feedback on the discussion paper is summarised in this report. This report represents the final stage of the project; a preferred framework for consumer participation and carer participation across Mental Health ACT and recommendations for its implementation.

## The Framework

The *Framework for consumer participation and carer participation across Mental Health ACT* sets out the principles for participation and the structures required for continuous improvements to the quality of relationships between consumers, carers and staff of Mental Health ACT, and the quality of services. Integral to participation is growth of individuals, groups and organisations. The *Framework* recognises the varying degrees of readiness for participation and values constant reflection and evaluation to support the growth of all individuals, groups and organisations.

The *Framework* acknowledges the need for systemic change that will support genuine consumer participation and carer participation. Its focus is on organisational development, workforce development and resourcing that will build capacity within Mental Health ACT and the community. The *Framework* then details strategies for consumer participation and carer participation in policy development, service planning, implementation and evaluation, individual advocacy and systems advocacy, staff development and research.

## Recommendations

The following recommendations are made for the implementation of the Framework;

1. Employ a Participation Coordinator to oversee implementation of the Framework.
2. Support establishment of a structure to provide training, recruitment and support to carers undertaking participation roles.
3. Recruit to the vacant Consumer Consultant position.
4. Explore options for employment of Advocates to provide individual consumer advocacy.
5. Set up Consumer Advisory Meeting and Carer Advisory Group.
6. Re-commence Quarterly Community Forums according to revised format.
7. Review funding for community organisations that have a role in participation, to ensure that funding is consistent with expectations and demands placed upon such organisations.
8. The *ACT Government Community Engagement Manual*<sup>5</sup> is utilised in the planning stage of all mental health consultations conducted by ACT Health to ensure compliance with government policy and good practice.
9. The following timeframe is recommended for implementation
  - 2007–2009 – Implement framework in current format
  - 2008–2009 – Work with Aboriginal and Torres Strait Islander people and organisations to develop culturally appropriate strategies
  - 2008–2009 – Work with culturally and linguistically diverse background people and organisations to develop culturally appropriate strategies.

# Introduction

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Increasingly, consumers and carers are sitting at the table where decisions are made about the services they use. Historically however, mental health services have been designed by health professionals and administrators and delivered to the community. Consumers and their family or other carers have had little or no opportunity to provide ideas or input to how the services they receive should be operated to better meet their needs. Over the past two decades there has been a shift in this top-down approach so that health professionals and administrators are beginning to include consumers and carers in decision-making about service development and delivery. Mental Health ACT is already involving consumers and carers in a range of ways across the organisation, for example on committees, employment of consumer consultants and in provision of staff education.

Consumer participation and carer participation are recognised in the *National Standards for Mental Health Services*<sup>1</sup>. Standard 3 is dedicated to participation stating, ‘Consumers and carers are involved in the planning, implementation and evaluation of the mental health services’<sup>1</sup>.

## Project rationale and methodology

In March 2006 Mental Health ACT engaged a project officer to work with consumers and carers to develop a framework for consumer participation and carer participation across the organisation. This initiative came in response to a review of clinical services of Mental Health ACT, recommendations from consumer consultants and feedback received from other consumers and from carers.

The project officer worked with a steering committee consisting of a consumer representative, an ACT Mental Health Consumer Network representative, two carer representatives, representatives from the Mental Health Community Coalition, the Public Advocates Office, ACT Community Health, and the Children of Parents with a Mental Illness Project Officer. It was considered important that the project be an example of a highly participative activity.

The first stage of the project involved consultation with consumers, carers and key informants through focus groups and interviews. These consultations, together with a review of the literature and advice from the steering committee, lead to the development of a discussion paper. *Come to the table: a discussion paper* presented a proposed model of participation for consumers and carers across Mental Health ACT. The paper was widely advertised for public comment. During the eight-week consultation period, feedback was received by various avenues, for example, focus groups, a phone-in and email. The feedback on the discussion paper is summarised in this report. This report represents the final stage of the project; a preferred framework for consumer participation and carer participation across Mental Health ACT and recommendations for its implementation.

## Feedback received on *Come to the table: a discussion paper*

The discussion paper was available for download from the ACT Health website and hard copies were available from the project officer. The paper was widely advertised using formal and informal mechanisms throughout the eight-week consultation period.

The vast amount of feedback received on the discussion paper exceeded the expectations of the Project Steering Committee, demonstrating that consumer and carer participation is an issue of great importance to many individuals and organizations in the ACT. The committee expresses its appreciation of the high quality of the feedback received and acknowledges the effort required to provide this.

Written feedback was received from 30 individuals and service providers, and verbal feedback was received from five individuals and service providers. Individuals who provided feedback were consumers, carers and academics with expertise in participation. Service providers were either government or community organisations that work with consumers and or carers, or with young people.

Much of the feedback is incorporated into the final framework outlined in this paper. Some of the feedback contained details specific to the implementation of the framework and therefore will be addressed at the time of implementation.

Generally, respondents were pleased with the work being undertaken by Mental Health ACT to improve consumer and carer participation across the organisation. Most respondents were complimentary of the proposed model, providing suggestions for minor improvements. Some respondents were critical of the model and very challenging in their suggestions for improvement. This diversity of feedback was appreciated by the Steering Committee as it prompted the group to challenge a number of assumptions previously made.

A number of themes emerged in the analysis of the feedback. A summary of the feedback is reported here under these themes.

## Theoretical context

The Ladder of Participation<sup>2</sup> as described in the discussion paper triggered much debate throughout the consultation period. Opponents of the ladder expressed concern that use of the ladder implies a hierarchical and paternalistic approach, and places greater value on some types of participation over others. It was argued by some respondents that the ladder perpetuates the use of tokenistic strategies for participation. A significant number of respondents argued for the increased participation of consumers and carers in high-level decision-making. There was agreement that the degree to which participants can influence outcomes must be stated for every participation activity.

As an alternative to the Ladder of Participation, which is largely based on a service provider model, it was suggested that consideration be given to consumer models for participation. These models place value on the process or journey of participation. They value opportunities for building trust and respect, where reciprocal learning is nurtured. Respondents reported on the success of several consumer models of participation developed elsewhere in Australia, for example the *Understanding and Involvement Project*<sup>3</sup> and the *Lemon Tree Learning Project*<sup>4</sup>.

The following comments were also received:

The most appropriate framework would be one that balances contemporary models of participation with organisational readiness.

If participation is meaningful, it is likely to be challenging for service providers.

It would be beneficial if participation were linked with concepts of recovery, given that participation is a part of recovery. It was also suggested that a framework for participation in mental health be linked with participation in the broader health sector.

Timeframes for participation activities must take into account the needs of consumers and carers and should be negotiated at the beginning of any participation activity with stakeholders.

Participants need feedback on the effectiveness of their participation.

A range of communication strategies must be used to ensure effective participation by those community members who do not have access to email or the internet, or who are unable to read or write.

## Mental Health ACT Workforce Development

Mental Health ACT could consider employing staff with training or experience in community development, in order to enhance the involvement of consumers and carers in the organization.

Applicants for positions in Mental Health ACT could be required to provide referees that are consumers and or carers.

There was strong support for training for Mental Health ACT staff. Some thought that training which aims to improve attitudes and understanding of consumer and carer participation should be mandatory for staff.

There was agreement that consumers and carers should be involved in developing the content of such training, and involved also in the delivery of staff training.

## Consumer and carer development

For carers, ability to participate is often restricted by the limited time and energy available.

Several respondents wrote of the additional limitations upon them, as they are both a consumer and a carer. It was suggested that a 'Wellness Plan' could be developed to support consumers and carers to take time off when or if needed.

There was strong support for training for carers in participation activities. Training could be delivered by a community organization, and CIT Skills for Carers and the Health Care Consumer Association were suggested.

Prior to commencement on any committee, consumers and carers require a general induction to the organisation, Mental Health ACT as well as to the specific committee on which they will be working.

There is a need to support consumers and carers in participation roles. Roles requiring the provision of intense emotional support to consumers and carers, for example consumer consultants and peer support roles, are especially demanding. It was suggested that supervision, similar to that offered to health professionals, should be made available for consumers and carers in these roles. Ideally, someone other than the employer would provide this professional supervision.

Remuneration was often regarded as an essential element of participation. It allows consumers and carers to participate equally and reduces tokenism. Therefore, it is important that it is a realistic amount and it must not interfere with income support or rental rebate.

There was a clear message in the feedback of the importance of community organisations in sustaining participation of consumers and carers in Mental Health ACT and in the provision of systemic advocacy services.

There was support for the operation of a consumer group where consumer workers return to strengthen their perspective and reverse the stress that people encounter when they work in the system.

There is a need for increased recognition and funding for community organisations to recruit, train and support participants as well as conduct independent research.

There was strong support for the development of a structure to support carers for participation.

## Consumer and carer roles

The comments in this area can be grouped under a number of headings:

### *The differing roles of consumers and carers*

One respondent cautioned against treating consumer participation and carer participation as the same thing, arguing that the two groups can hold opposing views, and that these differences be recognised and accepted.

In contrast to this view, many respondents commented on the need for opportunities for consumers and carers to work together on issues. It was acknowledged that consumers and carers should be given a choice about whether they wish to work collaboratively on an issue.

When consumers and carers hold different views on a topic, it was suggested that this needs to be explained publicly, and any decisions that seek to resolve this issue fully explained.

Several respondents pointed out that it is not uncommon for an individual to identify as a consumer and a carer, which can therefore make any divide between consumers and carers problematic.

### *Employment*

Many respondents provided comment on the issue of employment of consumer and carer workers inside versus outside Mental Health ACT. Feedback was mixed, with support for both options. The common theme however was that advocacy roles should be performed by persons employed outside of Mental Health ACT, but that there remains a role for a consumer worker and carer worker within Mental Health ACT to work closely with staff.

A clear job description, connection with peers and good support were factors considered vital for consumers and carers being employed within Mental Health ACT.

### *Skill requirements*

Respondents endorsed the consumer representative and carer representative positions and stressed the importance of skills and knowledge among those undertaking these roles. Multiple respondents wrote of the necessity for representatives to be connected with their constituency so that they may represent the views of their constituency.

It was also suggested that a 'map' of all committees and corresponding representatives would be helpful.

The process for selecting representatives must be transparent and inclusive. One respondent stated that consumer or carer representatives should never be the only non-departmental person on a committee. Another respondent suggested a program for developing new representatives, to avoid representation work falling to a small group of people.



### *Role of consumer consultant and advocacy*

A strong message in the feedback was that consumer consultants should not provide individual advocacy services. The following tasks were recommended for consumer consultants:

- Assist with staff training and transition of staff attitudes
- Assist with orientation of new consumer workers
- Coordinate consumer roles in Mental Health ACT
- Facilitate collaborative relationships with stakeholders
- Be available for staff consultation
- Be a contact person for local or national inquiries
- Refer issues to the Consumer Advisory Meeting

It was suggested that the consumer consultant could chair the Consumer Advisory Meeting and could sit on the Mental Health ACT Executive. Another respondent expressed concern for the level of isolation of consumer consultants, suggesting that there be multiple consultants employed at any time.

According to several respondents, individual consumer advocates should be available for consumers who are going before the mental health tribunal, and to assist consumers to complete Recovery Plans in collaboration with Mental Health ACT staff.

There was a clear message that consumers employed to provide these individual advocacy services should be employed outside Mental Health ACT. It was recommended that the positions be developed with consideration for recognised consumer advocacy principles. One respondent stressed that it is unethical for consumers to provide any clinical type services. This respondent cautioned against blurring of consumer worker roles and mental health services.

Another respondent suggested that advocates be available for mental health consumers to provide advocacy regarding a range of issues, not only mental health.

### *Peer support*

Respondents acknowledged the potential value of peer support roles, particularly for reducing isolation. One respondent argued that Mental Health ACT has a right and a responsibility to supervise peer support programs. Feedback about the potential role of carers working alongside Crisis Assessment and Treatment Team (CATT) staff was positive, with the suggestion that carer peer support workers follow up with families the day after CATT intervention.

## **Feedback Forms and Satisfaction Surveys**

To prevent fear of reprisal, it was suggested that completed feedback forms and satisfaction surveys be managed by a community organization.

## Quarterly Community Forums

Respondents stressed the importance of a collaborative arrangement including consumers, carers, community organisations and Mental Health ACT.

Some suggested the forums be held as an opportunity for all consumers and carers involved in participation activities to describe to each other and the community the work they do. It was suggested that the Consumer Advisory Meeting and the Carers Advisory Group could come together at these forums.

## Community Consultations

Several respondents expressed concern that Mental Health ACT does not adhere to the ACT Government Community Engagement Guidelines<sup>5</sup> in conducting consultations with the community, for example the provision of six weeks for consultation periods.

Suggestions were made in the feedback for improving the accessibility of community consultations, including alternating locations, using formal and informal strategies and sending out any pre-reading in advance.

Several respondents wrote of the need to take measures to avoid consultation fatigue, for example, space consultations out, ensure people are trained, and ensure there is feedback to the community at the conclusion of any consultation process.

## Consumer Advisory Meeting and Carer Advisory Group

Respondents were generally very supportive of the Consumer Advisory Meeting and the Carer Advisory Group as proposed in the discussion paper. These were seen as an important opportunity for consumers and carers to meet with their own constituency to share information and expertise, and to formulate a consumer or carer response to emerging issues. Based on experiences in another state, one respondent stressed the importance of strong formal and informal connections between these bodies and consumers and carers who access the service.

The importance of connections with other decision-making bodies throughout the organization was also emphasised. This respondent cautioned against creating a structure that may lead to the Consumer Advisory Meeting seeing itself as the only voice for consumers.

Some respondents argued that the success of the Consumer Advisory Meeting and the Carer Advisory Group depends upon them being independently facilitated. The reason offered for this was that if the Advisory bodies are perceived as aligned with one consumer group or one carer group, this might create an impression of bias or lack of diversity.

A compromise position was offered by one respondent who suggested the groups be facilitated by a consumer group and by a carer group but have independent, democratically elected chairs.

## Diverse groups

Several respondents expressed concern that the proposed model did not attempt to incorporate the participation needs of Aboriginal and Torres Strait Islanders, people of culturally and linguistically diverse background, people who are gay, lesbian, bi-sexual and transgender and older persons.

## Young people

A significant number of respondents provided comment on the issue of participation of young people. It was clear from the feedback that the label 'young people' needs to be clearly defined and that future work in this area must be done in collaboration with a wide range of community and government organisations that work with young people.

## Evaluation of participation

Respondents stressed the importance of evaluation of participation activities. Some suggested that evaluation should incorporate the opinions of consumers and carers and that consideration be given to the development of key performance indicators for participation. There was support for the Consumer Advisory Meeting and the Carer Advisory Group to play a role in evaluation of participation.

## Implementation

The employment of a participation coordinator was considered by several respondents to be essential for the success of the model. It was suggested that a coordinator would play a valuable role in building capacity within Mental Health ACT as well as providing liaison with community organisations. It was also acknowledged that implementation of the model would require a staged process.

# Framework for Consumer Participation and Carer Participation across Mental Health ACT

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The *Framework for consumer participation and carer participation across Mental Health ACT* sets out the principles for participation and the structures required for continuous improvements to the quality of relationships between consumers, carers and staff of Mental Health ACT, and the quality of services. Integral to participation is growth of individuals, groups and organisations. The *Framework* recognises the varying degrees of readiness for participation and values constant reflection and evaluation to support the growth of all individuals, groups and organisations.

The *Framework* acknowledges the need for systemic change that will support genuine consumer participation and carer participation. Its focus is on organisational development, workforce development and resourcing that will build capacity within Mental Health ACT and the community. The *Framework* then details strategies for consumer participation and carer participation in policy development, service planning, implementation and evaluation, individual advocacy and systems advocacy, staff development and research.

## Participation through dialogue

Central to effective participation is reciprocal learning between consumers, carers and service providers. This type of learning occurs best when meaningful dialogue takes place in a safe environment. A dialogue process allows consumers, carers and service providers to discuss an issue in depth so that all participants may gain a deeper understanding of the perspectives of others. The *Understanding and Involvement Project*<sup>3</sup>, a consumer evaluation of an acute psychiatric hospital in Victoria identified several sites for deep dialogue;

- i) Consumer only groups
- ii) Decision making forums involving consumers and staff
- iii) Decision free settings involving consumers and staff engaging in “reflective, explorative, respectful ‘deep dialogue’ across difference” *Lemon Tree Learning Project*<sup>4</sup>

This consumer model for participation provides a useful tool for future planning and carrying out of participation activities across Mental Health ACT.

## Principles for participation

The following principles were developed by consumers, carers and representatives from ACT Health as fundamental to meaningful participation. They express the intentions of all participation activities and offer hope to the mental health community of the ACT.

1. Consumer participation and Carer participation recognises, promotes and safeguards the rights of Consumers and Carers. It embraces a human rights and social justice framework of rights, equity, access and participation.
2. Participation is highly valued and Consumers and Carers are recognized as providing a valuable service to Mental Health ACT.
3. Consumer participation and Carer participation has the purpose of improving service quality and delivery
4. Consumers and Carers have the right to influence decisions on ethical practice, policy, resource allocation and culture (work practice) and operation of the mental health services that serve them.
5. Consumer participation and Carer participation includes representation on decision making bodies, consultation, individual advocacy and systems advocacy, staff development and research.
6. Consumer participation and Carer participation is promoted at all levels of the organisation and takes place at the individual, service and system level including assessment and treatment processes, rehabilitation and recovery.
7. Participation in the service in any form, for example as a Consumer Consultant, a Consumer Representative or a Consumer making a complaint will not disadvantage their access and treatment to mental health services.
8. Participation activities recognise that the priorities of Consumers, Carers and service providers may differ, and hence remain flexible to accommodate differing requirements and resources.

9. Consumers and Carers are involved early in planning and evaluation processes to identify preferred consumer participation and carer participation strategies.
10. Time frames for participation are negotiated with Consumers and Carers in recognition of competing demands on their time in addition to the time and resources required to consult with their constituencies.
11. Consumer representatives and Carer representatives are selected by their constituency via an inclusive and transparent process.
12. Consumer Representatives and Carer Representatives report to, and receive direction from their constituent communities. Every effort is made by representatives to be accountable to their constituency to ensure a legitimate, democratic and transparent process.
13. Consumer organisations and Carer organisations are resourced to provide a professional, supportive and nourishing environment for those who chose to belong to an organisation as a basis for their participation involvement.
14. Consumers and Carers who participate receive feedback about how their participation is utilised.
15. Participation is valued from a range of Consumers and Carers at differing stages of wellness and with differing levels of knowledge of the mental health system.
16. Consumer participation and Carer participation includes a range of communication methods to ensure that every consumer and carer who wants to, can give feedback and be involved in dialogue about an issue.
17. Young people and children have the right to participate in decisions affecting them and to be supported to participate as fully as possible.
18. The benefits of participation in Mental Health ACT must be available to all Canberrans regardless of age, gender, disability, illiteracy, racial or ethnic background, income, creed or place of residence.
19. Consumer participation and Carer participation may mean conflicts arise and uncertainty can be expected. An inherent part of the process, these conflicts when managed with respect for all parties can help to improve the quality of services<sup>2</sup>.
20. Consumers and Carers who participate in activities alongside departmental officers are valued for their unique expertise and as such are remunerated for their time.
21. Advocacy from individuals and organisations who are independent of the health system is an essential component of quality improvement activity.
22. Consumers and Carers are encouraged to advocate for themselves and structures exist which support self-advocacy.

## Building capacity for participation

The term *capacity building* refers to ‘the development of sustainable skills, organisational structures, resources and commitment to health improvement in health and other sectors, to prolong and multiply health gains many times over’<sup>6</sup>. To ensure participation of consumers and carers is genuine, effective and sustainable over time, action is required in three areas; Mental Health ACT leadership and policy, Mental Health ACT workforce development, consumer and carer development.

### Mental Health ACT leadership and policy

A commitment to consumer and carer participation must be demonstrated across all levels of Mental Health ACT. The Mental Health ACT Executive can demonstrate this commitment by modelling genuine and innovative participation strategies and encouraging participation of consumers and carers to be built-in to decision making rather than added-on to the decision making processes. Mental Health ACT Executive and other leaders in the service have an important role to enable and support all staff to include consumers and carers throughout all levels of the organisation.

### Mental Health ACT workforce development

Mental Health ACT staff have most of their contact with consumers and carers when consumers are unwell or when there is a crisis. Therefore, staff may have a skewed perception of mental illness that does not account for wellness or include hope<sup>7</sup>. Mental Health ACT staff require opportunities to learn from consumers’ and carers’ experiences of mental illness when they are in a state of wellness and can discuss their experiences objectively. This will give staff a more holistic and realistic perspective.

### Consumer and carer development

Information about the different ways that consumers and carers can participate in Mental Health ACT should be made widely available. Similarly, a strategy for communicating recent and future changes to consumer and carer roles is required.

The participation of consumers and carers in some activities will require them to possess special knowledge and skills. For example, those who provide peer support require skills in active listening and knowledge of the mental health sector, mental illness, confidentiality and ethics<sup>8</sup>.

Consumers and carers who work as representatives require opportunities to meet with others from their constituency. This enables them to gain a fuller understanding of the issues and concerns of those they are to represent. Regular opportunities to communicate with their constituency are also important for passing information from Mental Health ACT to consumers and carers in the community. For effective representation, it is essential that representatives have access to a range of consumer or carer views. This would include the views of people of all age groups, people of culturally and linguistically diverse background, people who are Aboriginal and Torres Strait Islander, and people with differing experiences of mental illness and health, as examples.

In addition to information received from peers, consumers and carers are occasionally required to conduct extensive research in order to present an informed and independent position on an issue. The process and timelines of Mental Health ACT require flexibility to allow consumer and carer groups to carry out this work. The ACT Mental Health Consumer Network and the Community Coalition of the ACT have an important role to play in coordinating this work.

Several community organisations in the ACT currently provide training and support for consumer and carer roles. The valuable services provided and expertise of these organisations is integral to effective and sustainable consumer and carer participation. A strong partnership between Mental Health ACT and community organisations that supports participation of consumers and carers is essential for the enhancement of participation in the ACT.

Mental Health ACT must work in partnership with carers and existing community organisations to establish a structure for the recruitment, training and ongoing support of carers for representation roles.



## Actions:

1. Update the Mental Health ACT Consumer and Carer Participation Policy to ensure consistency with local policy documents, current research and resourcing.
2. Update duty statements to reflect the role that Mental Health ACT staff play in enhancing consumer participation and carer participation.
3. Provide opportunities for Mental Health ACT staff to gain skills, knowledge and attitudes which promote consumer participation and carer participation.
4. Provide Mental Health ACT staff with resources for participation including current literature, guidelines, tools and mentoring.
5. Update the Mental Health ACT publication *Providing feedback about our services* to include all opportunities for participation.
6. Work with community organisations to disseminate information about opportunities for participation and ensure a common understanding of consumer roles and carer roles.
7. Create a space on the Mental Health ACT website with information about participation, including the names of those involved on committees (with individuals permission).
8. In collaboration with community organisations, ensure ongoing training is available for all consumer participation and carer participation roles.
9. Review selection process for consumer representatives and carer representatives to ensure those selected have formal mechanisms for communicating with their respective constituency and do not carry out their role in isolation.
10. Negotiate resources required for participation activities with consumers and carers, including time, access to information and finances for conducting independent research.
11. ACT Health explore opportunities for recurrent funding for those community organisations integral to consumer participation and carer participation.

## Strategies for participation

Central to the *Framework* is recognition of the need for a range of strategies for consumer participation and carer participation. This range of strategies acknowledges that some consumers and carers will prefer involvement that relies on giving feedback about services they have received or were unable to access, whilst others will prefer involvement that is more active. Active participation provides opportunities for meaningful dialogue on issues of importance to consumers, carers and Mental Health ACT. No one type of participation is valued over another, and all participation is important for improving the quality of services.

The strategies for participation are divided into consumer participation roles, carer participation roles and general participation strategies. Common to all strategies for participation is the need to abide by the principles for participation identified above.

## Consumer participation roles

### Consumer Consultants

Consumer Consultants are employed within Mental Health ACT to provide consultation to Mental Health ACT staff on consumer perspectives and to promote consumer participation throughout the organisation. The promotion of consumer participation may require the Consumer Consultant to provide orientation for new consumer workers as well as participate in the delivery of staff education. Consumer Consultants may participate as a consumer representative, however are never involved in the provision of individual advocacy services.

For staff to consult with consumers it is necessary for them to have confidence in their expertise. Regular attendance at team meetings provides staff and Consultants with opportunities to build trusting relationships.

Consumer Consultants have formal and informal connections with other consumers. Through their interactions with staff and consumers, Consumer Consultants are likely to become aware of opportunities for improving the quality of services. The Consumer Advisory Meeting would provide an opportunity to discuss such systems advocacy issues. Consumer Consultants attend Consumer Advisory Meetings and Quarterly Community Forums to inform others of the work they are doing, to receive support, to be informed and discuss consumer issues with other consumers.

### Individual Consumer Advocacy

Individual Consumer Advocacy provides advocacy services for consumers of Mental Health ACT. The preferred model for advocacy, known as self-advocacy requires advocates to support consumers to advocate for themselves. Self-advocacy involves imparting of skills and knowledge so that consumers may advocate for themselves many times over. Only when it has been determined that a person is unable to advocate for themselves would an advocate provide individual advocacy, that is, advocate on behalf of the consumer.

Advocates work with consumers across the whole of Mental Health ACT. They attend Consumer Advisory Meetings where they can raise systems type issues. Advocates are employed outside of Mental Health ACT with an organisation able to work with a self-advocacy model.

### Consumer Representatives

Consumer Representatives provide a consumer perspective on decision-making bodies, during consultations, working groups, steering committees, on tender select panels and staff selection panels. Additionally, Consumer Representatives can play a valuable role in evaluation and research conducted by Mental Health ACT.

Consumer Representatives are trained and supported to carry out their role by the ACT Mental Health Consumer Network. They are democratically elected by their peers and have regular opportunities to consult with their constituency so that they are able to represent a range of consumer views. Training and selection of Consumer Representatives is consistent with the range of committees and other meetings that require differing types and levels of skills and knowledge. For example, a Consumer Representative with an ability to think strategically about whole systems from a consumer perspective will be required for a committee whose function is strategic planning. Consumer Representatives are recruited via the ACT Mental Health Consumer Network.

Participation of Consumer Representatives can include the use of deep dialogue with Mental Health ACT staff and carers. This would allow all parties an opportunity to gain a greater understanding of the perspectives of others. Such dialogue contributes to a deep understanding which often cannot be achieved in a formal decision-making setting.

## Consumer Educators

Consumer educators deliver education to Mental Health ACT staff on the consumer experience by telling their personal story. This model of education has been shown to be effective for increasing knowledge and reducing stigma. Consumer Educators are recruited through Mental Illness Education ACT.

## Consumer Peer Support Workers

Consumer Peer Support Workers are trained and supported to provide support to consumers with a similar diagnosis to their own. The aim of this service is to reduce isolation and improve opportunities for recovery. Consumer Peer Support Workers are currently recruited, trained and supported by the Mental Health Foundation

## Consumer Advisory Meeting

Coordinated by the ACT Mental Health Consumer Network, the Consumer Advisory Meeting is an opportunity for Consumer Consultants, Consumer Advocates, Consumer Representatives, Consumer Educators and Consumer Peer Support Workers to meet regularly. The purpose of the meeting is to identify and discuss consumer issues in addition to provide support to each other. Meetings provide a venue to discuss any new and recurrent issues of concern for consumers.

Participants decide at the meeting upon the most appropriate strategy for managing issues that arise, for example via a report to the Mental Health ACT Executive, or via a representative on a particular committee. The Consumer Advisory Meeting provides advice to Mental Health ACT on the participation of consumers within Mental Health ACT. A member of the Mental Health ACT Executive attends the Consumer Advisory Meetings to assist with flow of information between Mental Health ACT and consumers.

The receipt of regular information from other participation strategies such as Consumer Feedback Forms and Satisfaction Surveys assists the Consumer Advisory Meetings to address the needs of a large range of consumers.

The terms of reference for the Meeting are determined by participants. Meetings are held quarterly and spaced between Quarterly Community Forums. Meetings are arranged by the ACT Mental Health Consumer Network who provides secretariat support also.

## Actions:

12. Recruit to the vacant Consumer Consultant position.
13. Work with consumers and relevant community organisations to develop duty statements for the following consumer roles;
  - a. Consumer Consultants
  - b. Consumer Advocates
  - c. Consumer Representatives
14. Seek funding for development of Individual Consumer Advocacy positions.
15. Review rate of reimbursement for Consumer Representatives.
16. Continue to work in partnership with ACT Mental Health Consumer Network, Mental Illness Education ACT and the Mental Health Foundation.
17. Explore opportunities for expanding effective Consumer Peer Support services in the ACT.
18. Provide funding for the establishment of the Consumer Advisory Meeting.
19. Develop a strategy for forwarding information to the Consumer Advisory Meeting which is gained through Consumer Feedback Forms and Satisfaction Surveys.

## Carer participation roles

### Carer Representatives

Carer Representatives provide a carer perspective on decision-making bodies, during consultations, working groups, steering committees, on tender select panels and staff selection panels. Additionally, Carer Representatives can play a valuable role in evaluation and research conducted by Mental Health ACT.

Carer Representatives are recruited via the Mental Health Community Coalition. Currently however, there is no funding to provide training and support for carers to carry out these roles. Additionally, carers are not being selected by their peers and there is no guarantee that a Carer Representative has regular opportunities to consult with their constituency so that they are able to represent a range of carer views. This issue is addressed above in 'Capacity Building'.

## Carer Educators

Carer educators deliver education to Mental Health ACT staff on the carer experience by telling their personal story. This model of education has been shown to be effective for increasing knowledge and reducing stigma. Carer Educators are recruited, trained and supported through Mental Illness Education ACT.

## Carer Peer Support

Carer Peer Support Workers are trained and supported to provide support to carers whose family member or friend is accessing or has accessed Mental Health ACT services. This service recognises the challenges frequently faced by carers and offers hope and support. Carer Peer Support Workers are recruited, trained and supported by Carers ACT.

## Carer Consultant and Carer Advocate

Carers frequently express concern about the small number of carers available to fulfil carer participation roles. It appears there is strong support for carers to participate in representative, education and peer support roles, however minimal support is expressed for specific Carer Consultant and Carer Advocate roles.

Further work is required to clarify the need for Carer Consultants and Advocates and to ensure the most effective model is utilised. This model would recognise the value within Mental Health ACT of consultancy by carers, and the need for individual advocacy for carers by their peers. Consideration should be given to expanding existing carer roles to include some consultancy and advocacy duties. It is recommended that Mental Health ACT seek opportunities for researching carer roles of consultancy and advocacy.

## Carer Advisory Group

The Carer Advisory Group is an opportunity for Carer Representatives, Carer Educators and Carer Peer Support Workers to meet for the purpose of identifying and discussing carer issues in addition to providing support to each other. Meetings provide a venue to discuss any new and recurrent issues of concern for carers.

The Group decides upon the most appropriate strategies for managing new issues, for example via a report to the Mental Health ACT Executive, or via a representative on a particular committee. The Carer Advisory Group provides advice to Mental Health ACT on the participation of carers within Mental Health ACT. A member of the Mental Health ACT Executive attends the Carer Advisory Group to assist with flow of information between Mental Health ACT and consumers.

The receipt of regular information from other participation strategies such as Consumer Feedback Forms and Satisfaction Surveys assists the Carer Advisory Group to address the needs of a large range of carers.

The terms of reference for the Group are determined by participants and the chairperson is elected by participants. Meetings are held quarterly, and spaced between Quarterly Community Forums.

Mental Health ACT currently convenes the Carers Advisory Group. Consideration should be given however, to a structure similar to that proposed for the Consumer Advisory Meeting, whereby meetings would be convened by a carer organisation. It is anticipated this would enhance the perceived and actual independence of the group.

### **Actions:**

20. Review rate of reimbursement for Carer Representatives.
21. Review hours of carer peer support program and increase promotion of the service throughout Mental Health ACT.
22. Expand Carer Peer Support Worker role to include some consultancy and advocacy duties in the absence of Carer Consultants and Carer Advocates.
23. Consider opportunities to research models for carer consultant and advocacy roles.

## **General Participation Strategies**

### **Consumer Feedback Forms**

Mental Health ACT, being part of ACT Health has a Consumer Feedback Form which can be used by consumers and carers to provide compliments, suggestions or complaints about services they have received or have been unable to access. The forms can be completed by consumers and carers or by staff who receive verbal feedback from consumers and carers. Feedback received via the Consumer Feedback Forms is collated and managed by the Patient Safety and Quality Unit of ACT Health according to the ACT Health Consumer Feedback Standards. These standards ensure feedback is used to initiate improvements to the quality and safety of services through the Mental Health Clinical Practice and Quality Improvement Committee.

### **Satisfaction Surveys**

Mental Health ACT conducts satisfaction surveys periodically to gather feedback from people who have used the service. Satisfaction surveys are conducted by Mental Health ACT and by an independent organisation, Press Ganey. Information gained by both surveys assists with prioritising and actioning quality improvement initiatives.

There is increasing evidence of the value of involving consumers and carers in evaluating mental health services<sup>9</sup>. Involvement of consumers and carers in the design and evaluation of satisfaction surveys will assist Mental Health ACT to gain feedback that is relevant to consumers and carers and can be used to direct quality improvement initiatives.

## Community consultations

Mental Health ACT holds consultations regarding specific issues throughout each year. When arranging consultations, the *ACT Government Community Engagement Manual*<sup>5</sup> is used by Mental Health ACT to assist in the design of a consultation strategy that will effectively engage the community in decision-making processes.

## Quarterly Community Forums

The Quarterly Community Forums provide consumers and carers who are involved in participation roles, with an opportunity to update other consumers and carers on the current issues and work they are engaged with. Importantly, these Forums bring consumers and carers together and the agenda is set by consumers and carers rather than an organisation. Consumers and carers who are not aligned to a consumer or carer organisation are encouraged to attend.

A partnership between the ACT Mental Health Consumer Network, the Mental Health Community Coalition, Carers ACT and Mental Health ACT, the Quarterly Community Forums are independently facilitated. With representatives from each of these organisations present, participants at the Forum can choose to refer particular items to them for follow up.

The timing of Quarterly Forums would alternate with meetings of the Consumer Advisory Meeting and Carer Advisory Group. The time and frequency of meetings requires regular review to reflect the competing demands placed on the consumers and carers.

### Actions:

24. Explore strategies for increasing the visibility of Consumer Feedback Forms for carers and consumers.
25. Provide regular summaries (de-identified) of feedback from Consumer Feedback Forms to Consumer Advisory Meeting and Carer Advisory Group.
26. Adhere to the *ACT Government Community Engagement Manual*<sup>5</sup> for all community consultation processes.
27. Re-commence Quarterly Community Forums according to revised format.

## Participation of young people

As with participation of the general community, young people have a right to be involved in decision making about services that affect their lives. *Young people* refers to persons up to the age of 25 years. Young people can come into contact with mental health services as consumers of the service, or when they have a friend or family member, such as a parent or sibling who accesses the service. It is not uncommon for young people to take on caring roles when they have a family member or friend experiencing mental illness.

The benefits of participation for young people are thought to be similar as for the general population. Meaningful and ethical participation provides opportunities for young people to inform services about their experiences with mental illness as a consumer, family member, friend or carer<sup>10</sup>. Participation also enables young people to describe their own efforts to maintain wellness for themselves or their cared for person, and to inform of the impact of work performed by adults on their behalf<sup>10</sup>. The genuine involvement of young people in the design and delivery phases is found to result in higher quality services<sup>11</sup>. Recent research has demonstrated that participation of young people is related to improvements in resilience for participating individuals<sup>12</sup>.

Strategies for engaging with young people must be developed with consideration of the different needs and resources of young people compared with the general population. A range of strategies is required to ensure engagement with a range of young people. Consideration should be made of the preferences of young people for participation, as well as the number and capacity of young people able to take on these roles. The most effective strategies will be those designed in partnership with young people and organisations that work directly with young people. It cannot be assumed that young people will participate through recognised community or government mental health organisations.

Organisations who work with young consumers, family members or carers of someone with mental illness, require the capacity to support young people for a variety of participation roles. For young people to participate as representatives, advocates, peer supporters and educators, specific training and ongoing support is required. Further work is required to clarify the possible ways that young people can participate and to identify the most appropriate organisations to support these roles and activities.

Young people require opportunities for dialogue with mental health service providers. Consideration should be given to a forum similar to the Consumer Advisory Meeting. This forum could provide a safe place for young people to come together to share stories, gain support and input to Mental Health ACT service development and delivery. A procedure for connecting this forum with the Consumer Advisory Meeting, Carer Advisory Group and the Quarterly Community Forums is essential.



### **Actions:**

28. Develop partnerships with young people and organisations that work with young people, to identify ways that young people prefer to participate.
29. Explore opportunities for development of Mental Illness Education ACT to include young people as educators.
30. Explore opportunities for development of peer support program to include young people as peer support workers.
31. Support young people and respective organisations to come together as a young peoples mental health participation forum.

## **Diverse Populations**

The ACT population represents a large range of culturally diverse peoples. In the 2001 population census 1.3 % of the Canberra and Queanbeyan population indicated they were Aboriginal or Torres Strait Islander<sup>13</sup>. The census found that 22.2% of people in the ACT were born overseas. It is well recognised that the health needs of this diverse population differs according to different understandings of health and community, and different historical and current relationships with service providers.

The need for, and potential benefits of participation of Aboriginal and Torres Strait Islanders and people from culturally and linguistically diverse backgrounds is clear. These populations currently access services at reduced rates compared with the general population, and are rarely involved in formal participation with Mental Health ACT. It is recognised that the strategies for participation of these groups will likely be different to those for the general population and the strategies outlined in the *Framework* may not meet the needs of these populations.

### **Actions:**

32. Develop partnerships with Aboriginal and Torres Straight Islander individuals, groups and organisations to identify and implement culturally appropriate strategies for participation.
33. Develop partnerships with culturally and linguistically diverse individuals, groups and organisations to identify and implement culturally appropriate strategies for participation.

## Evaluation

Practices relating to consumer participation and carer participation have expanded significantly in the ACT in the past decade. This expansion has occurred in response to national and local agendas, however minimal evaluation of these practices has occurred to date. A program for rigorous evaluation will assess whether models and strategies being utilised are achieving their objectives, are consistent with contemporary theoretical and conceptual knowledge about participation. Importantly, evaluation of participation practices will assess whether finite resources are being used in the most cost effective way.

Routine evaluation contributes to a process of continuous improvement. Planning for evaluation commences at the beginning of any participation activity with the identification of goals and objectives. Evaluation of consumer participation and carer participation is mindful of the processes as well as outcomes of participation, and is consistent with the principles of participation. Whilst the number of opportunities for participation is important, a thorough evaluation would also consider the quality of participation opportunities from the perspective of consumers and carers.

Evaluation of participation across Mental Health ACT would occur at a number of levels;

1. The effectiveness of the *Framework* as a whole, for example whether it is able to capture the views of a large range of consumers and carers.
2. Progress of capacity building within Mental Health ACT and the community to support participation.
3. The effectiveness of each strategy of participation.
4. Compliance with the principles of participation.

### Actions:

14. Identify tools for evaluation of consumer participation and carer participation.
15. The Consumer Advisory Meeting, Carer Advisory Group and Mental Health ACT work collaboratively to develop a program for evaluation.

# Recommendations

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The following list of recommendations was developed following lengthy consultation with the community. The recommendations are listed with corresponding actions from the *Framework* and approximate 12-month budgets (at September 2006)

## 1. Employ a Participation Coordinator

The Participation Coordinator would be responsible for overseeing the implementation of the *Framework*. It is recommended this be a full time position.

Actions: 1-7, 10, 13, 15, 17, 20, 22-25, and 28-35

Budget: \$111 023 per annum, including operating costs

## 2. Support establishment of a structure to provide training, recruitment and support to carers undertaking participation roles

Currently there is no structure to support carers to work as carer representatives. Such a structure would work closely with existing carer organisations to recruit, train and support carers. It is recommended this be established within an existing organisation.

Actions: 13

Budget: \$55 000 per annum

## 3. Recruit to the vacant Consumer Consultant position

To minimise isolation, increase support and increase the impact of the Consumer Consultant role it is recommended that the vacant position be filled.

Actions: 12

Budget: Funding for this position is already available

## 4. Explore options for employment of Advocates to provide individual consumer advocacy

Further exploration of the Individual Consumer Advocacy services is required to ensure the positions are located within an organisation that is supportive of a self-advocacy model. Two part time positions are recommended.

Actions: 14

Budget: \$74 900, including operating costs

## 5. Set up Consumer Advisory Meeting and Carer Advisory Group

It is recommended that these groups be set up within the community. To cover costs of venue, catering, secretariat and facilitation it is estimated the cost would be approximately \$6000 per annum per group.

Actions: 18

Budget: \$12 000

## 6. Re-commence Quarterly Community Forums according to revised format

The revised format for the Quarterly Community Forum recommends a partnership between Mental Health ACT, the ACT Mental Health Consumer Network, Carers ACT and the Mental Health Community Coalition of the ACT. Funding is required to cover costs of venue, catering, secretariat and facilitation.

Actions: 27

Budget: \$6000 per annum

## 7. Review funding for community organisations

Review the funding for community organisations that have a role in participation to ensure consistency with expectations and demands placed upon them. This would consider current and future demands

Actions: 8, 11, 16, 21, and 22

Budget: Not applicable at this stage

## 8. The ACT Government Community Engagement Manual<sup>5</sup> is utilised in the planning stage of all mental health consultations conducted by ACT Health

The ACT Government Community Engagement Manual<sup>5</sup> is an ACT Government policy offering a guide to consulting with the community in a genuine and meaningful way.

Actions: 26

## 9. The following timeframe is recommended for implementation

2007–2009 – Implement framework in current format (Actions 1–31, 34, 35)

2008–2009 – Work with Aboriginal and Torres Strait Islander people and organisations to develop culturally appropriate strategies (Action 32)

2008–2009 – Work with culturally and linguistically diverse background people and organisations to develop culturally appropriate strategies (Action 33)

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The Flannel Flower used in this publication is an adaptable and enduring Australian native wildflower that grows across the country in all extremes. It has been chosen by the Mental Health Council of Australia as a symbol of mental health awareness for its strength and resilience.

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