CONSUMER AND CARER PARTICIPATION POLICY

a framework for the mental health sector

developed by the National Consumer and Carer Forum
FOREWORD

It is impossible to overemphasise the importance to mental health consumers and carers of participating in decision making at all levels concerning the mental health services that affect our lives.

We would like to acknowledge the important steps towards consumer and carer participation that have been taken in the last 20 or more years. However, whilst mental health has been the leader for the health sector in this regard, it is also necessary to acknowledge that there is still need for more to be done. The continued commitment and cooperation of consumers, carers, policy makers and health care professionals is absolutely essential.

To assist with this process, the National Consumer and Carer Forum (NCCF) has developed this policy as a guide to be used by all participants involved in mental health within the public, private and non-government sectors for the development and / or implementation of consumer and carer participation policies. We have done this to reflect the content of the National Mental Health Plan 2003-2008, which has been endorsed by all Australian Governments. The Plan states:

Consumer and carer participation and partnership at all levels in policy, planning and treatment is a hallmark of a quality mental health system… However, participation at other policy and planning levels, and participation in service planning and delivery across the spectrum of care from promotion and prevention to recovery, has not yet been achieved.

The policy aims to cover all levels of participation, and includes consumer and carer input at individual, local, state, and national levels. Our hope is that all those involved in the mental health sector will either adopt in full or adapt this document to suit their local needs. The document is intended as an example of best practice for a consumer and carer participation policy.

We look forward to the day when the principles outlined in this document have become standard practice for the entire mental health sector.

Finally, we would like to thank all the consumers and carers who have contributed to the development of the policy, and the State, Territory and Australian Government Mental Health Directors who have funded this work.

Ms Janet Meagher AM  
Mr Tony Fowke AM
Co-Chairperson,  
Co-Chairperson,
National Consumer and  
National Consumer and  
Carer Forum  
Carer Forum
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While the evaluation reports of the First and Second National Mental Health Plans under the National Mental Health Strategy highlighted the achievements in progressing consumer and carer participation, they also reported that there is still much to be done before full consumer and carer participation is achieved. The evaluations identified the central role that consumers and carers are required to play in the planning, development, implementation, delivery, and evaluation of services. It is hoped this document will assist in guiding this participation.

The findings of these reports also highlighted that much work remains in the reform of mental health systems. The National Mental Health Plan 2003-2008, released in September 2003, further builds on the successes, outcomes, and evaluations of the First and Second National Mental Health Plans, to form one part of the renewed National Mental Health Strategy.

The renewed Strategy includes the National Mental Health Policy, the Mental Health Statement of Rights and Responsibilities, the National Mental Health Plan 2003-2008, and the Australian Health Care Agreements. The renewed Strategy is further enhanced through documents such as the National Standards for Mental Health Services, the National Action Plan for Promotion, Prevention and Early Intervention for Mental Health 2000, and the National Action Plan for Depression.

Australian Government funding to State/Territory Governments for mental health care is delivered through the broader Australian Health Care Agreements.

Consumer and Carer Participation

Consumers and carers are each recognised as having unique expertise and understanding due to direct experience or close observation of mental illness. A considerable body of research strongly supports effective and responsive partnerships between consumers, carers and professionals, with the benefits enduring and contributing to improved quality of life and social adjustment for both consumers and carers.

Furthermore, consumers and carers are directly impacted by the quality and effectiveness of mental health care and thus may be considered the key stakeholders in mental health. Consumer and carer participation in determining mental health practices and priorities ensures a sound basis for successful processes, programs and services to maintain and improve the mental health of all Australians.

Currently, a universally agreed-upon working definition of consumer and carer participation does not exist. For the purposes of this document, consumer and carer participation may be defined as:
The aim of consumer and carer participation is to improve the quality of service delivery through participation in development, implementation, and evaluation, and increase the level of consumer and carer satisfaction with mental health services.

All participants involved in the mental health sector must display a high level of commitment and belief in the value of consumer and carer participation, for it to be truly effective rather than just tokenistic.

Roles, responsibilities, and reporting mechanisms are important considerations when consumer and carer participation involves representation on committees established to progress mental health issues.

Consistent with the Mental Health Statement of Rights and Responsibilities:

 Individuals seeking promotion or enhancement of mental health care or protection when suffering mental health problems or disorders have the right to contribute and participate as far as possible in the development of mental health policy, provision of mental health care and representation of mental health consumer interests.

Along with this right comes the responsibility of consumers and carers to actively contribute and participate in committees/forums where they are representing the perspective of consumers, carers, or an organisation. In addition, reporting mechanisms, either verbal or written, are required to ensure transparency and clarity in such representation and to ensure the body being represented is kept well informed of activities, processes and outcomes.

For participation to lead to strong partnerships, the input and contributions of all stakeholders, including those of consumers, carers, special needs groups, clinical service providers, private mental health service providers, non-Government and Government organisations, Aboriginal and Torres Strait Islander groups, and State/Territory peak mental health bodies, needs to be valued, respected, and appreciated. With such recognition, there is an expectation that all groups will willingly and actively contribute their special expertise and knowledge, and provide valid representation. With such collaborative practice and sharing of special expertise from all key stakeholders, the mental health sector is in a greater position to promote the mental health of all Australians and assist in enhancing mental health outcomes.

Either voluntary or paid participation by consumers and carers in all aspects of mental health care.

This includes individual treatment plans which affect the lives of consumers and carers, through sharing of information and opinions, policy development, education and training of mental health workers, formal or informal planning, delivery, implementation and evaluation of all activities associated with the mental health sector, as well as in all processes that invest consumers and carers with legitimate decision making power.

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1 The NCCF provides a medium for mental health consumers and carers to come together to foster partnerships, provide input into the activities of the Mental Health Council of Australia (MHCA), and through the auspice of the Council, input into the reform of mental health policy and service delivery in Australia. The NCCF is supported and resourced by the MHCA, and funded through the Australian Government and jurisdictional contributions. The NCCF reports through the MHCA’s Consumer and Carer Committee to the MHCA Board. The NCCF is the only body specifically furthering the partnership between mental health consumers and carers at the national level. Further, it is the strongest and most equitable voice for consumers and carers at the national level. The structuring of the NCCF provides representation with an equal voice for consumers and carers from each of the states and territories, and brings together the peak national consumer and carer bodies from around Australia.

2 Reference throughout this document made to a National Mental Health Strategy recognises the development of an initial National Mental Health Strategy that ran from 1993–1998. The strategy was revised at the end of this period, and again in 2003. In this document, the revised Strategy is referred to as the renewed National Mental Health Strategy that covers the periods 1998–2003 and 2003–2008.

3 For example, the National Mental Health Report 2000, the Evaluation of the National Mental Health Strategy, the Evaluation of the Second National Mental Health Plan, Out of Hospital Out of Mind.

4 National Mental Health Policy, National Mental Health Plans, National Mental Health Statement of Rights and Responsibilities, the Medicare Agreements (the Australian Healthcare Agreements).


BEST PRACTICE PRINCIPLES FOR INCLUSION IN A PARTICIPATION POLICY

The following best practice principles have been identified as necessary steps for implementing consumer and carer participation, and are presented as a standard benchmark for mental health organisations to aim for when promoting and practicing consumer and carer participation.

1. Core Principles

Consumers and carers provide unique expertise due to their lived experience of mental illness

It is of fundamental importance for all mental health organisations and for all individuals involved in mental health to recognise that consumers and carers each have unique expertise and understanding due to direct experience or close observation of mental illness.

Consumer and carer participation will be promoted at all levels of mental health care

It is necessary for all mental health organisations to acknowledge and promote, through practice, consumer and carer participation in all processes that affect the lives of consumers and carers.

These processes cover participation at the individual, local, regional, state, and national level, and include participation in activities such as:

- individual treatment, recovery and relapse prevention plans;
- recruitment;
- resource allocation;
- planning;
- service delivery;
- education and training of the mental health workforce;
- programs for increasing community awareness of mental illness;
- mental health promotion and illness prevention;
- research – design, conduct, reporting and dissemination;
- evaluation; and
- continuous quality improvement processes.

Consumers and carers have distinct and separate needs

All public, private and non-government mental health organisations will recognise the distinction between consumer and carer issues and needs, and acknowledge that it is generally inappropriate for consumers to represent the interests of carers, and for carers to represent the interests of consumers.

Mental health organisations will seek formal and informal links with peak bodies for jurisdictional representation

Each State/Territory will have a recognised peak mental health body representing that State or Territory, with consumers and carers involved in the management and operation of the organisation, and which operates for the benefit of both people with mental health problems or disorders and their carers.

All mental health organisations are encouraged to seek formal and informal links with the peak mental health body of that State/Territory, as well as with relevant consumer and carer groups.

Mental health organisations are encouraged to adopt or adapt this participation policy to local needs

All public, private, and non-government mental health organisations will have a consumer and carer participation policy that adopts the principles and practices outlined in this document. Where necessary, mental health organisations will adapt this document to suit individual needs and to ensure it is ‘locally owned’.

Mental Health organisations are therefore encouraged to adopt or adapt this policy as a means of governing and guiding consumer and carer participation.

Mental health organisations will need to adapt to the particular communication and participation needs of representatives

Some organisations may need to consider the use of advanced communication technology to enable the participation of consumers and carers living in rural and remote areas including for example tele, online and video conferencing.

Similarly, the communication needs of people with disability should be accommodated. The use of interpreters might also be needed in certain instances to assist the participation of those whose first language is other than English or those with hearing impairment.
2. Principles for defining the role of consumer and carer representatives

The role of consumer and carers representatives is to be clearly defined for all staff members.

Terms of Reference and Duty Statements will be developed for consumer and carer representation and participation. This will ensure clarity and transparency in the roles and responsibilities of all such representative positions.

The Terms of Reference and Duty Statements will be made available to other staff members to help ensure understanding and acceptance of the roles and responsibilities of consumer and carer representatives.

Consumer and carer representatives have responsibilities to fulfil

Consumer and carer representatives have the responsibility to participate in discussions, decision-making and activities, and ensure the views of the constituency they are representing are adequately portrayed.

Further, consumer and carer representatives have additional responsibilities including performing appropriate preparation work, consultation with constituencies, and reporting back (either verbally or in writing) to the body they are representing on the outcomes of their representation.

Mental health organisations will be prepared for ill health affecting consumers and carers

Mental health organisations will have appropriate processes in place in the event that consumers or carers are unable to participate due to ill health of themselves or the person for whom they care.

Mental health organisations will have conflict resolution processes in place

Mental health organisations will have conflict resolution processes in place. Information about these processes will be included in the training provided to consumer and carer representatives. Where and if conflict arises between consumer and carer representatives and other parties, the organisation’s conflict resolution processes should be used.

Disciplinary action may be required should a consumer or carer representative or another staff member fail to follow organisational policies, and where systematic processes fail to affect change.

Where disciplinary action is necessary, consumer and carer representatives should be subject to the same organisational policies and procedures as other staff or board members. Steps must be followed to ensure the representative is fully informed, and therefore has the opportunity to respond.

Complaints should be taken seriously and must be dealt with quickly. This includes providing feedback to the person making the complaint. Complaints should be used as a part of the quality management process. Complaints should not affect professional relationships once the issue has been resolved.

3. Principles for selection of consumer and carer representatives

Mental health organisations will select appropriately supported consumer and carer representatives

When considering consumer and carer participation, the selection process will ensure applicants are sought from recognised and relevant consumer and carer groups who are resourced and able to provide support and a network for consultation, for example, local, State/ Territory, national, public, private, and non-government consumer and carer peak bodies.

Mental health organisations will select appropriately skilled consumer and carer representatives

All mental health organisations (Government, private, NGOs and others) will engage consumers and carers with relevant expertise to participate in all processes and activities that affect the lives of consumers and carers.

In engaging consumers and carers, mental health entities have a responsibility to seek representatives with appropriate expertise and access to the constituency they represent. For example, that expertise and constituency may relate to the particular illness a consumer or carer may have experience of (e.g. depression; schizophrenia, anxiety disorder), or to expertise and constituency provided by special needs groups (e.g. Aboriginal, non-English speaking background, rural and remote).

Mental health organisations will have transparent processes for the selection of consumer and carer representatives

All mental health organisations (Government, private, NGOs and others) will have transparent and accountable selection and appointment processes for engaging consumer and carer representatives. The selection and appointment processes should be documented and records kept of how decisions are made. These processes should not impose an unnecessary cost imposition on any organisation involved.

Mental health organisations will provide information to assist with the recruitment of consumer and carer representatives

All public, private, and non-government mental health organisations promoting and practicing consumer and carer participation will maintain information to assist with the
recruitment of consumers and carers who have agreed to be available for participation. In accordance with principles of privacy and confidentiality, agreement should be established with each participating consumer and carer about:

- the information to be listed;
- who can be given what information; and
- the process by which the consumer or carer can be contacted by a third party seeking representatives.

Keeping this information will ensure there is a broad network of consumers and carers who are easily contactable and readily available to participate.

Mental health organisations have a responsibility to ensure a range of consumer and carer views are represented.

4. Principles for employment of consumer and carer representatives

Consumers and carers will be remunerated for representative duties

Unless otherwise agreed by consumers and carers, they will receive payment for their representative participation\(^7\) and reimbursement of expenses (e.g. travel and meals) incurred during their recognised active participation in externally organised mental health activities and processes that affect their lives. Consumers and carers should not be required to bear the costs of participation and representation expenses.

Reimbursement for such engagement will be negotiated between consumers and carers and the organisation on a paid or volunteer, part-time or full-time basis. It is important that all conditions regarding payment and expenses for representation be established upfront.

In the absence of established rates of pay, remuneration should follow the rates and conditions for holders of part-time public office set by the Australian Government Remuneration Tribunal, the independent statutory authority established under the Remuneration Tribunal Act 1973 (Cwth). Should funding be insufficient to meet these costs, rates for consumer and carer participation should be negotiated with their organisation, or in the case of independent consumer or carer consultants with the individual concerned.

Remuneration should also take into account the amount of time it may take to prepare for a meeting. This preparation time is often extensive, particularly when considering the amount of paperwork and material that is expected to be read prior to high-level meetings. There is often minimal recognition of such preparation time for consumers and carers, which may often involve taking time out of their daily business or using outside-work hours to prepare.

Often, other representatives may prepare for their representative duties (which may be an inherent component of their employment) during their working day and be remunerated through their salary to do so. However, many consumers and carers who undertake advocacy and representative duties may do so through personal interest and may not necessarily be able to undertake preparation for representative activities during their normal working day.

Consumer and carer representatives will receive relevant and necessary ongoing support, education, training and resourcing

All public, private, and non-government mental health organisations will provide ongoing support, education, and training for consumers and carers on their rights and responsibilities as consumer and carer participants and contributors in all processes that affect their lives, including research\(^8\) and the planning, development, implementation, and evaluation of mental health services.

Mental health organisations will also provide any relevant education and training usually provided to fellow staff members such as computer training, office familiarisation, occupational health and safety practices, governance and the roles responsibilities of committee and board representation. Consumers and carers with special expertise will participate in staff education and orientation activities in all public, private, and non-government mental health organisations in order to benefit consumers and carers and other staff members.

Furthermore, mental health organisations will also provide those resources reasonably expected for consumer and carer representatives to perform their duties, such as a workspace, stationery, a computer, and a telephone.

Mental health organisations will utilise consumers and carers as educators

Consumers and carers will be employed by mental health services, government, private, NGOs and external agencies as people who have expertise, to educate and inform regarding all processes and activities that affect their lives (consumer consultant model).

Employers will involve consumers and carers when ensuring all staff are aware of the roles and responsibilities of consumer and carer representatives and of the expertise they bring to the position.

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\(^7\) That is, participation where the individual is providing a consumer perspective or a carer perspective rather than participation in the management of treatment for their mental health problem or mental illness.

\(^8\) Consumer and carer participation in research may reflect the degree to which the research impacts on their lives. Consumer and carer involvement in research will be acknowledged appropriately in research reports. See for example: Griffiths K M, Christesen H, Barney L, Jenkins A, Kelly C & Pullen K. Promoting consumer participation in mental health research: Workshop Report, Centre for Mental Health Research Australian National University, 2004, www.anu.edu.au/cmhr
DEVELOPING A CONSUMER AND CARER PARTICIPATION POLICY

The following issues are presented for consideration in the development of a consumer and carer participation policy. Once implemented, such a policy will ensure organisations are held accountable for consumer and carer participation in its fullest capacity.

Components for Inclusion in a Consumer and Carer Participation Policy

1. The purpose of the policy should be clear, achieved through a concise statement of purpose or aim.

2. The policy should be grounded by a set of principles that reflect the value the organisation places on consumer and carer participation. For example:

   - consumers and carers have a right to participate and have a direct and active role in all processes that affect their lives;
   - consumers and carers with appropriate skills and expertise should be appointed to represent the interests of consumers and carers;
   - priority should be given to the appointment of consumers and carers who are members of groups able to provide support and a network for consultation;
   - a single person should not be appointed to represent the views of both consumers and carers. Both a consumer and a carer representative are required to represent the views of each respective group;
   - participation of consumers and carers is an essential component of continuous quality improvement;
   - communication links between the organisation and consumers and carers are effective two-way processes. Information is shared and exchanged with consumers and carers to enable effective participation;
   - the organisation recognises the need for resources and support for the consumer and carer participation process to enable effective participation;
   - opportunities are provided for the ongoing support and relevant training and education for consumers and carers to assist in their effectiveness as consumer and carer representatives; and
   - consumers and carers must be aware that responsibilities are associated with participation, primarily the active contribution to quality improvement processes.

Mental health organisations will ensure adequate information flows and feedback mechanisms

All public, private, and non-government mental health organisations will ensure adequate feedback mechanisms exist to facilitate information flow between the organisation and consumers and carers. Examples include:

- satisfaction and evaluation surveys;
- focus groups;
- support groups;
- regular meetings with local, State / Territory representatives;
- public, private, and non-government community advisory groups;
- newsletters;
- mental health consumer and carer networks;
- meetings with senior management;
- websites;
- consumer and carer representation on steering committees;
- reference groups; and
- State / Territory ministerial committees.

All mental health organisations will also endeavour to ensure consumer and carer representatives are provided with all relevant information necessary to their duties in a timely manner in recognition of the need to absorb as well as consult with relevant constituencies.

It is important to recognise that many consumers and carers may not have had the same educational or employment opportunities as other staff members and may therefore be unfamiliar with jargon and with technical or complex discussions. All staff members will endeavour to avoid unless necessary overly technical or complex jargon that can act as a barrier to consumer and carer participation.

When such language is unavoidable, and when consumer and carer representatives join an organisation after the relevant project has commenced, appropriate briefings will be provided in order to fully prepare them for representative duties.

Review and evaluation of consumer and carer participation will occur annually

An evaluation and ongoing review process of consumer and carer participation will occur annually within all public, private, and non-government mental health organisations, to ensure sound principles and practices are maintained and mental health organisations remain accountable for their actions. This may occur in conjunction with continuous quality improvement processes and accreditation against the National Standards for Mental Health Services. Following the review process, policies and practices will be changed where required to reflect the outcomes of the evaluation.

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3. The policy should articulate the organisation’s position in relation to consumer and carer participation in:

- strategic planning for the organisation;
- service planning;
- staff recruitment, orientation and training;
- service delivery;
- service implementation;
- service evaluation;
- health decision-making; and
- resource allocation and development.

4. The policy should state:

- the responsibilities of all parties in implementing the policy;
- what measures will be taken to monitor the policy’s implementation;
- whether and when the policy should be reviewed; and
- how the policy will be evaluated (including consideration of what measures or indicators may be used in the evaluation).

CHECKLIST

Does the consumer and carer participation policy:

1. state a clear purpose?
2. have a set of principles that reflect the value the organisation places on consumer and carer participation?
3. articulate the organisation’s position in relation to consumer and carer participation in:

- strategic planning for the organisation;
- governance;
- committee and Board Representation;
- service planning;
- service delivery;
- service implementation;
- service evaluation;
- research;
- staff recruitment, training and orientation;
- health decision-making; and
- resource allocation and development.

4. The policy should state:

- state responsibilities of all parties in implementing the policy;
- what measures will be taken to monitor the policy’s implementation;
- whether and when the policy should be reviewed; and
- how the policy will be evaluated (including consideration of what measures or indicators may be used in the evaluation).

5. state what measures will be taken to monitor the policy’s implementation?
6. state whether and when the policy should be evaluated and revised?
7. state how the policy will be evaluated (including consideration of what measures or indicators may be used in the evaluation)?
8. ensure the service promotes consumer and carer participation in all processes that affect the lives of consumers and carers?
9. include consumers and carers in every process that affects their lives, for instance:

- recruitment;
- workforce;
- resource allocation;
planning;
√ service delivery;
√ research;
√ evaluation; and
√ other processes as suggested by local circumstances and issues.

allow for the employment of consumers and carers with special expertise to participate in all processes and activities that affect their lives.

promote the employment of consumers and carers by external agencies (e.g. accrediting agencies) to participate in all processes and activities that affect their lives?

ensure Terms of Reference and Duty Statements are developed for consumer and carer representation and participation on all committees?

ensure consumer and carer representatives on committees abide by reporting mechanisms, either written or verbal, upon completion of their representation?

adopt the principles and practices outlined in the Consumer and Carer Participation Policy and adapt them to suit local need?

of a State/Territory peak body ensure consumers and carers are involved in the management and operation of the organisation?

ensure processes are established for the payment of consumer and carer participation and reimbursement of their expenses resulting from their active participation?

ensure adequate feedback mechanisms exist to facilitate information flow between the organisation and consumers and carers?

ensure consumers and carers with special expertise participate in staff education and orientation activities within the organisation?

ensure the organisation provides ongoing support, education and training for consumers and carers about their rights and responsibilities in relation to their participation?

ensure requests for employment or representation of consumers and carers is sought from key consumer and carer groups who are able to provide support and a network of consultation?

maintain information to assist the recruitment of consumers and carers who have agreed to be available for participation?

REFERENCES

Australian Health Ministers’ Conference April 1992, National Mental Health Policy, Australian Government Publishing Service, Canberra


Australian Health Ministers July 1998, Second National Mental Health Plan, Mental Health Branch, Commonwealth Department of Health and Family Services, Canberra

National Mental Health Report 2000; Sixth Annual Report, Changes in Australia’s Mental Health Services Under the First National Mental Health Plan of the National Mental Health Strategy 1993-98, Commonwealth Department of Health and Aged Care, Canberra

National Standards for Mental Health Services, endorsed by the Australian Health Ministers’ Advisory Council’s National Mental Health Working Group December 1996, Mental Health Branch, Commonwealth Department of Health and Family Services, Canberra


National Action Plan for Promotion, Prevention and Early Intervention for Mental Health 2000, National Mental Health Strategy, Mental Health and Special Programs Branch, Commonwealth Department of Health and Aged Care, Canberra


USEFUL RESOURCES AND LINKS

- Australian Infant, Child, Adolescent and Family Mental Health Association [www.aicafmha.net.au](http://www.aicafmha.net.au)
- Centre for Mental Health Research Australian National University [www.anu.edu.au/cmhr](http://www.anu.edu.au/cmhr)
- Consumers Health Forum (Australia) [www.chf.org.au](http://www.chf.org.au)
- National Centre for Consumer Participation in Health [www.participateinhealth.org.au](http://www.participateinhealth.org.au)
- Auseinet – Australian Network for Promotion, Prevention and Early Intervention for Mental Health [www.auseinet.com](http://www.auseinet.com)