

# **CONSUMER AND CARER INVOLVEMENT**

## ***GETTING STARTED***

### **A KIT COMPRISING:**

- 1. A BASIC MODEL FOR PRIVATE PSYCHIATRIC HOSPITAL-BASED CONSUMER AND CARER ADVISORY COMMITTEES**
- 2. CONSUMER PARTICIPATION, FIRST STEPS – A CASE HISTORY**
- 3. MENTAL HEALTH COUNCIL OF AUSTRALIA CONSUMER AND CARER PARTICIPATION POLICY TEMPLATE**

**A BASIC MODEL FOR  
PRIVATE PSYCHIATRIC HOSPITAL-BASED  
CONSUMER AND CARER  
ADVISORY COMMITTEES**

An initiative of Ms Janne McMahon, Private Psychiatric Sector Consumer Representative to:

- ?? Strategic Planning Group for Private Psychiatric Services (SPGPPS)
- ?? Chair, National Network of Private Psychiatric Sector Consumers and Carers
- ?? Board Member of the Mental Health Council of Australia

## **PREAMBLE**

It is recognised that Consumers and Carers are in a unique position to express and comment on the strengths and weaknesses of the mental health services delivered within the private sector. Consumer and Carer Advisory Committees provide excellent forums that enable Consumers and Carers to come together for information sharing and to provide input to the services delivered by a Hospital.

The following sample information is provided to assist hospitals who wish to establish Consumer and Carer Advisory Committees and, as such, is intended to be a guide only.

## **PRINCIPLES**

- ?? To provide a framework for Consumer and Carer input into services delivered.
- ?? To set clear parameters and identify areas for Consumer and Carer input.
- ?? To provide a mechanism for advice to and from hospitals management.
- ?? To be able to advise the Consumers and Carers of the development, progress of projects, delivered or conducted within the services, as appropriate.
- ?? Be a point of reference for hospital management.
- ?? To advise on the *National Standards for Mental Health Services* as they apply to the private sector.
- ?? To advise and give input on the National Mental Health Strategy and the Third National Mental Health Plan 2003-2008.
- ?? To advise on Accreditation processes as they apply to Consumer and Carer participation in the private hospital setting.

## **BENEFITS FOR HOSPITALS**

A Hospital-based *Consumer and Carer Advisory Committee* enables hospital management to seek advice and feedback on what the needs of Consumers and Carers are in relation to inpatient, day patient, program and community service provision.

## **BENEFITS FOR COMMITTEE MEMBERS**

It is hoped to auspice the continuing mental wellness for members, enabling them to grow in confidence and expertise in advocacy. This will then enable them to be role models for other Consumers and Carers and improve staff/consumer, staff/carer relationships and gain a better understanding for all parties. It is expected that the Committee will gain greater awareness of the constraints within which service provision is determined.

## **BENEFITS FOR THE CONSUMER AND CARER POPULATION OF THE HOSPITAL**

A Consumer and Carer Advisory Committee should be able to adequately represent the views of consumers and carers accurately and independently.

The Committee should be a point of contact for needs and concerns of Consumers and Carers to be articulated and expressed to the hospital management, as appropriate.

## **INDEPENDENCE**

The initiative is intended to provide autonomy for the Consumer and Carer Advisory Committee whilst Management has input into the ongoing viability, areas of input and appropriateness of comment.

## **OUTCOMES**

It is anticipated that positive gain will be achieved with direct and greater Consumer and Carer input into the planning, delivery and evaluation of initiatives, and delivery of services within the Hospital.

## **EXAMPLE OF TERMS OF REFERENCE FOR A HOSPITAL-BASED CONSUMER AND CARER ADVISORY COMMITTEE**

- 1. Provide an opportunity for the involvement and opinions of Consumers and Carers.**
- 2. To advise, and be advised, in relation to issues which affect consumers and carers.**
- 3. Provide a mechanism for advice and to evaluate individual concerns or complaints referred to the Consumer and Carer Advisory Committee by hospital management.**
- 4. Facilitate ideas and provide views to hospital management on ways to improve services through exploration of difference service models as appropriate.**
- 5. Provide information and advise Consumers and Carers of progress and development of projects referred to the Committee by Management.**
- 6. Be a point of reference for Consumers and Carers to express their needs and concerns regarding services provided within the Hospital and communicate their views to hospital management.**
- 7. To provide input into resources such as patient information brochures and patient satisfaction surveys.**
- 8. To be an advocate for patients that do not feel comfortable dealing with a complaint.**
- 9. To advise on the *National Standards for Mental Health Services* as they apply to the private sector and to areas relevant to Consumers and Carers.**
- 10. To advise on the Accreditation process as they apply to areas of Consumer and Carer participation.**
- 11. To advise and give input on the National Mental Health Strategy and the Third National Mental health Plan 2003-2008.**

## **EXAMPLE OF OPERATING GUIDELINES FOR A HOSPITAL-BASED CONSUMER AND CARER ADVISORY COMMITTEE**

It is recognised that Consumers and Carers are in a unique position to express and comment on the strengths and weaknesses of the mental health services delivered within the private sector.

The Consumer and Carer Advisory Committee exists primarily as a forum to enable hospital management and Consumers and Carers to come together for information sharing, and to provide input to the services delivered by the Hospital.

### **OBJECTIVES**

The Terms of Reference underpin the objectives of the Committee.

### **DEFINITIONS**

**Consumer** A person who receives, or has received, care delivered within the private sector mental health service.

**Carer** A person whose life is affected by virtue of a relationship, close association and caring role with a consumer who receives, or has received, care delivered within a private sector mental health service.

**Constituency** Means the individual units of a Hospital i.e. inpatient, day patient, day program, elderly assessment, child and adolescence, community services, veterans etc.

**Hospital Management** Consists of the Chief Executive Officer, Director of Clinical Services/Director of Nursing, Heads of Departments.

### **MEMBERSHIP**

Membership of the Committee will be influenced by the size of the hospital. In larger Hospitals some Committee are constituted as follows.

4 Consumer members

2 Carer members

1 member of the staff of the hospital

Each member of the Committee should be appointed for a reasonable period of time (for example 2 years). It is suggested that, following the establishment year, half of the positions on the Committee, that is 2 Consumer members and 1 carer member should become vacant so that half of the Committee is replaced each year.

In the establishment year, it is suggested that appointment be made by hospital management for 1 Carer member and 2 Consumer members for a

period of 12 months with the appointment of one further Carer member and two Consumer members for a period of 2 years. Outgoing members may re-nominate.

The Chair and Deputy Chair should be drawn one from each constituency and should form the leadership. Both positions should become vacant after each 12 month period and the position filled by self nomination and a majority vote of the members of the Committee.

## **COMPLAINTS MECHANISM**

Any complaints or concerns of members should be resolved by the Committee and, if that process cannot resolve the issue, then a decision by the Chair and Deputy Chair together, shall be binding with hospital management being informed. If this process still cannot resolve the complaint, then the Executive of the Hospital shall make a decision, which will be binding.

## **ROLES**

The role of the Chair should be to oversee the function of the Committee, report to hospital management on the outcome of meetings, and together with the Deputy Chair as appropriate, discuss issues with management and prepare the agenda for the meetings.

The role of the member of the staff of the Hospital should be to provide clarification and advice as sought by the Committee and record the minutes.

## **WHAT IS EXPECTED OF MEMBERS**

- ?? Members are should be expected to represent the views and experiences drawn from Consumers or Carers as the case maybe, from within the Hospital's services and ensure these views are accurately and adequately represented.
- ?? It is important that members are aware that their views and those of the people they represent need to be, or have the potential to be, of major significance in the way the hospital services are delivered.
- ?? To provide appropriate input through the Committee to hospital management.
- ?? To recognise the opportunity of providing a collaborative and united view and provide advice on issues relating to Consumers and Carers and act as an advisory capacity to hospital management.

## **DISCIPLINE OF MEMBERS**

The Committee with a majority vote, and with the agreement of hospital management should be able to remove any individual member and appoint an interim alternate where that member, in the opinion of the Committee, has persistently and willfully acted in a manner prejudicial to the interest of the Committee.

## **MENTORSHIP**

Each Consumer member, and if requested each Carer member, should be allocated a service provider as a mentor. This partnership enables the opportunity for support and debriefing and improved staff/consumer and staff/carer relationships and understanding for all parties.

## **NOMINATIONS TO THE COMMITTEE**

Nominations to the Committee should be drawn from Consumers and Carers of the Hospital. It should be by way of self nomination in writing, seconded by a permanent member of the Hospital staff. A meeting should be called each 12 months for the purpose of filling the vacancies on the Committee and consumers and carers present should be able to vote on their preferred choice of candidate. Appointments should then follow an interview process by a panel comprising the Chair or Deputy Chair, as the case may be, 1 current member of the Committee, and 1 member of Management, totaling 3 members.

## **VOTING RIGHTS**

Voting rights should be restricted to the Consumer and Carer Committee members only. In the event of a tied vote, the Chair should have a second and deciding vote.

## **MEETINGS**

Ordinary meetings of the Committee should be held each quarter.

Interim meetings should be at the request of the hospital management.

Minutes should be recorded, ratified by the members and forwarded to the hospital management by the Chair, together with a proposed action list of items requiring attention within 21 days of the holding of the meeting.

Each member should be responsible for representing their constituency.

## **PAYMENT TO MEMBERS:**

Any payment should be by way of an honorarium. The rate of \$50.00 per member per meeting attended limited to the 4 meetings per annum has been used by some facilities. The timing of meetings should be two and a half hours duration.

If at the request of hospital management, specially convened meetings are arranged, then each member attending should be paid at the same rate of \$20.00 per hour or part thereof.



If the Committee requires further meetings beyond the 4 meetings per year, then this should be deemed voluntary attendance. An approach to hospital management can be sought and, if deemed appropriate, payment should be at the discretion of hospital management.

These conditions should be reviewed annually by the hospital management, together with the Chair and Deputy Chair.

## **TRAINING AND EDUCATION**

Training in the areas of advocacy, facilitation, confidence and self care should be undertaken, including training in the use of *The Kit*. Education about the way services are delivered, constraints, funding implications etc. shall be undertaken by the most appropriate member of the staff of the hospital or the staff member of the Committee, whichever is most appropriate.

## **AREAS OF RESTICTION:**

The Committee should have no input in any way whatsoever into the areas of human resource, finance, administration, contractual arrangements between private health insurance funds, unless specifically requested by hospital management.

## **CONFIDENTIALITY**

The members of the Committee should be bound by confidentiality of printed material, verbal discussion specifically identified by the Chair which should not be for distribution, citation or discussion outside of the Committee.

## **REVIEW**

The terms and conditions of the Operating Guidelines should be reviewed each 2 years except upon joint agreement between the Committee and Management.

## **EVALUATION**

To be able to assess the impact of participation by Consumers and Carers in the planning, delivery and evaluation of the services provided and delivered by the Hospital, it is necessary to establish the current position at the commencement of the Consumer and Carer Advisory Committee. To provide a baseline assessment, an evaluation needs to be undertaken to establish what participation exists, in what areas, what are the attitudes of Consumers, Carers, Staff and the hospital management.

The evaluation should be repeated and assessed at yearly intervals by hospital management together with the Chair and Deputy Chair, to establish the effectiveness of the Consumer and Carer Advisory Committee and determine any barriers which exist, or have the potential to exist and ways to overcome them.

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<sup>1</sup> *The Kit: A guide to the advocacy we choose to do - "A resource Kit for consumers of mental health services and family carers*, National Mental Health Strategy, Australian Government Department of Health and Ageing, 1998.

## **DISBANDING THE COMMITTEE:**

By way of a majority vote of hospital management, the Hospital reserves the right to disband the Committee as it sees fit, if the Terms of Reference are breached or the Committee becomes dysfunctional.

## CONSUMER PARTICIPATION, First Steps – A Case History

### Introduction

This paper has been written in the hope that by sharing the detail of the initiation of the Wesley Health Services Consumer and Carer Advisory Committee, that we may help others in their endeavours towards consumer participation.

The focus is on the broad sweep of the organisation involved in setting up the Advisory Committee, however, during that process Working Party members often needed to pause and give reflection to the subtleties of the shift from consumer focus to consumer participation. While this is no indication for less responsibility on behalf of the Mental Health Care Worker it does involve a “giving over”. Decisions are made *with* the consumer not *for*. This has been, at an individual level, a best practise pursuit for some time, however consumer participation as an organisational policy lends a new authority to consumer involvement. Janet Meagher says it best

Consumer involvement is about the ways and means of creating partnership:

Of consumers being actively involved.

- In decision making about service provision, and more completely....
- In decision making about choices which affect their lives.

The committee is for both consumers and carers – and it is hoped that through carer representation the hospital will be able to work more effectively in areas of aftercare and support

Along the way we received a great deal of assistance – not least from our own Group Manager, Bernard McNair. Bernard has had an interest for along time in consumer participation and he gave support, advice, imparted enthusiasm and pointed us towards the efforts of others. We were allocated the important resources of time and opportunities for education and for this we thank Bernard and the Wesley Mission.

Toowong hospital, Queensland has generously shared their experience of building consumer participation while Janne McMahon has given formative advice and valuable support.

<p>May 2001</p> <p>Establish of Consumer Participation Working Party</p> <p>Initial Research and Networking</p>	<p>Wesley Health and Counselling Services takes the first steps towards formalised consumer participation. A committee of six staff members was convened from two centres – Wesley Private Hospital and Wandene Private Hospital. This was a time of research and networking. Contact was made with Toowong Hospital in Queensland; they had already established a consumer committee and were able to provide us with a copy of their Terms of Reference.</p> <p>Committee Members review <i>The Kit</i> and three members attended <i>Improving Health Services Through Consumer Participation</i> run by the Consumer Focus Collaboration &amp; Australian Council for Safety and Quality in Health Care.</p>
<p>August September October</p> <p>Exploration of Models of Consumer Participation</p>	<p>Throughout these months the committee explored different models of consumer participation – committee sizes and constitutions, scope, methods of appointment, communication and reporting lines, the role our hospital representative would play, hours, remuneration, and throughout this we were discussing what ‘consumer participation’ meant for us. We all brought our experience, greater or lesser, to the table.</p>
<p>November</p> <p>Drafting a Consumer Participation Policy &amp; Terms of Reference for a Consumer Advisory Committee</p> <p>Staff Education</p>	<p>This committee now became the <u>Consumer Participation Working Party</u> with the declared purpose of forming a <u>Consumer Advisory Committee</u>, drawn from the Consumer and Carer population. We drew up a draft Terms of Reference – this was worked over and revised many times in the next few months.</p> <p>While we were going to the consumer/carer population another task was to inform the treating Psychiatrists and staff working within the hospital of the planned committee. First our Group Manger took this to the Medical Advisory Committees and we looked at ways in which we could reach and inform all staff members. The ideas we went with were;</p> <p>I) A folder in the staff room containing <i>Fact Sheets</i> from the National Resource Centre for Consumer Participation in Health (<a href="http://nrccph.latrobe.edu.au">http://nrccph.latrobe.edu.au</a>)</p> <p>ii) A letter to be circulated to all staff with their payslips</p>

<p>December</p> <p>Planning for the Establishment Of the Consumer Advisory Committee</p> <p>Holding a public Information forum</p>	<p>Material, which needed to be considered in the setting up of the committee, kept reaching us. There were two invaluable documents. The first was the <i>National Consumer and Carer Participation Template</i> from the Mental Health Council of Australia and contained guidelines for best Practice Principles for inclusion in Participation Policy. The second was the <i>Proposed Model for a Hospital Based Consumer and Carer Advisory Committee</i>. This was from Janne McMahon and provided the framework for our efforts.</p> <p>These works effected a redrafting of the Terms of Reference; this model was now based on a committee of six consumers/carers and a Hospital Representative drawn from hospital staff. This committee would report through to the Hospital Executive.</p> <p>The initial committee would be chosen by representatives of the Working Party and from there by self-nomination to the Consumer Advisory Committee. The Terms of Reference contained details of tenure. Over the following months a staff member is sought for the position of Hospital Representative.</p> <p>Conversations with Janne McMahon also focussed us on resources and facilities that should be offered to committee members. Education is an essential and this, together with mentorship became an agenda item and reached resolution in the new year. Other considerations were defining a meeting place, administrative support, storage space, refreshments and reimbursement, to be offered.</p> <p>It was decided to hold a public meeting in February for interested consumers/carers; we aimed to co-ordinate our efforts towards that date.</p> <p>The work was gathering momentum and called for several meetings during December. In common with many workplace several of our members would be on leave in January so our planning need to encompass their absence.</p> <p>Contract with consumer/carers was to be made through a mail out, this raised questions of privacy and confidentiality and to this end the solicitor for Wesley Mission was consulted. Our hospitals' Admission Policy now covers this eventuality with its Consent Form. A letter was drafted inviting all those who had been admitted to Wesley Private hospital or Wandene Private hospital either as an inpatient or an outpatient, in the last calendar year.</p> <p>Care was taken that all options were available for the</p>
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	<p>RSVPs (fax, phone email and post), the slip for return by post also included further options,</p> <ul style="list-style-type: none"> <li>i) I will be able to come to the information evening on February 13<sup>th</sup> 2002.</li> <li>ii) Please do not contact me any further</li> <li>iii) I cannot attend but please send me any further materials.</li> </ul> <p>The plan was to send this letter out towards the end of January inviting the recipients to a Consumer Participation Forum in February. It was at this meeting that we hoped to attract candidates for the Consumer Advisory Committee.</p>
<p>January 2002</p> <p>Mail out for Information Forum</p>	<p>Eight hundred letters are mailed on January 19<sup>th</sup>. A member of the Working Party is available to receive replies and give further information if needed.</p>
<p>February</p> <p>Information Forum is held.</p> <p>Consumer/carer are sought for committee positions</p>	<p>The Information evening is held, of eight hundred invitations there had been eighty replies – many more than expected. Serving supper took on a new dimension, but the kitchen staff rose to the occasion. The format of the evening was to present the draft of the Terms of Reference to the audience and through this the aims and structure of the proposed committee were communicated to the audience.</p> <p>Questions from the consumer/carers included matters of committee selection, resources available reimbursement, training, criteria for selection of committee members (and whether consumer/carers could have input) and queries as to how much time a that committee member would need to allocate.</p> <p>Consumer/carers who were interested in playing a role on the Consumer Advisory Committee were asked to fill out a form to notify the Working Party. Those who did not wish to be active but wanted to be informed of the committee's work could given indication of this. Those who had not been able to attend but were interested had been sent a copy of the draft Terms of Reference and an application forms.</p>
<p>March</p> <p>Preparation for Interview for committee positions.</p>	<p>Applications are received. To create a short list a letter was sent, asking for answers to four questions. These questions were constructed to give indication of advocacy strengths ie 'Do you feel you have a specific understanding of a particular mental illness which would enable you to advocate for others?</p> <p>Questions for interview were also given consideration – each interviewee was to receive the same questions in an interview that would last for forty minutes. The aim in</p>

	<p>these interviews was to determine the candidates availability (transport and time) and again of course advocacy skills. After much discussion we had decided to focus on areas of communication, confidence, an understanding of both the need for confidentiality and the need for consultation, empathy and an ability to look for solutions.</p>
<p>April</p> <p>Interviews Selection Orientation of Committee members</p>	<p>The interviews took place over two days in April. An early decision was made and all candidates were promptly informed.</p> <p>In mid April an Orientation Day took place Accompanied by the Hospital Representative the new committee visited he three sites of Wesley Health Care, Wesley Private hospital Wandene Private Hospital and Carlingford Day Centre. During these visits the committee had the opportunity to meet key people they were then made welcome by the Group Manage and Introduced to the Medical Superintendent over lunch in the boardroom of Wesley Health and Counselling Services.</p>
<p>May</p> <p>Education</p>	<p>The Committee attended the <i>Consumer Advocacy Training</i> at the Institute of Psychiatry, Cumberland Hospital North Parramatta NSW. They were accompanied by the Hospital Representative and the Convenor of the Working Party. this provided much information on the background of consumer movement</p> <p>The first meeting of the new committee is scheduled.</p>
<p>June</p> <p>Mentorship</p>	<p>The Mentoring Program has taken shape. Again this was a result of research and a working group. The members of this group have produced guidelines, created a brochure and made contact, signalling their availability, with members of the Consumer Advisory Committee. The mentors' role has been defined as To function as an internal dialogue partner who can offer relevant guidance, interpretations of events, and specific feedback during the schedule one-to-one sessions between mentors and mentees and as a source who offers constructive critiques from the vantage point of personal experience, professional knowledge and present organisation attitudes and views.</p>
<p>August</p>	<p>The Working Party feels that it's work is complete. This</p>

Progress of Consumer Advisory Committee	<p>has been a prologue to the Consumer Advisory Committee that is now well established as a report from the Hospital Representative indicates. Their achievements to date have included</p> <ul style="list-style-type: none"><li>- The appointment of a Chairperson and Deputy Chairperson</li><li>- Contact with national support network and a meeting with the Adelaide Representative</li><li>- Attendance at a Carer Information Day at Rozelle Hospital</li><li>- Topic identified for possible project – this is being researched to determine viability.</li></ul>
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# CONSUMER AND CARER PARTICIPATION POLICY TEMPLATE



*Promoting the mental health of all Australians*

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# CONSUMER AND CARER PARTICIPATION POLICY TEMPLATE

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- **BACKGROUND**

## Purpose

The Mental Health Council of Australia<sup>1</sup> endorses this document as a guide for all mental health services within the public, private and non-government sectors, to utilise in the development of consumer and carer participation policies.

While the current processes and initiatives of Commonwealth, State/Territory, non-government, and private mental health organisations in promoting consumer and carer participation in mental health service delivery are recognised and acknowledged, this template is presented for consideration in the development of a consumer and carer participation policy which will attempt to address identified gaps and ensure consumer and carer participation exists in its fullest capacity.

## National Mental Health Strategy<sup>2</sup>

The progress of Australia's mental health service delivery is well documented<sup>3</sup>. The establishment and focus of the *National Mental Health Strategies* is clearly to improve the quality of mental health service delivery in Australia. A central platform to these improvements was the realisation that

***consumer and carer input is essential if improvements in service delivery are to be achieved.***

The *National Mental Health Strategies* and the documents which underpin them<sup>4</sup> have put in place principles, objectives and strategies to guide the continual reform and required changes within the Australian mental health sector, including those activities required to improve consumer and carer participation.

The evaluation report of the initial *National Mental Health Strategy* highlighted the achievements in progressing consumer and carer participation. The evaluation identified the central role that consumers and carers are required to play in the planning, development, implementation, delivery, and evaluation of services.

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<sup>1</sup> The Mental Health Council of Australia (MHCA) is the peak, national, non-government organisation established to represent and promote the interests of the Australian mental health sector ([www.mhca.com.au](http://www.mhca.com.au))

<sup>2</sup> 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. At the end of this period, the Strategy was revised. In this document, the revised Strategy is referred to as the renewed *National Mental Health Strategy* which covers the period 1998 – 2003. Reference to a third *National Mental Health Strategy* is intended for implementation at the end of the period of the renewed *National Mental Health Strategy*.

<sup>3</sup> For example, the *National Mental Health Report 2000*, the *Evaluation of the National Mental Health Strategy*.

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

The findings of the evaluation of the initial *National Mental Health Strategy* highlighted that much work remains in the reform of mental health systems. This resulted in the extension of the *National Mental Health Strategy* for implementation over a further period from 1998 to 2003. The renewed *National Mental Health Strategy* attempts to build on the successes, outcomes, and evaluation of the initial *National Mental Health Strategy*.

The policy framework of the renewed Strategy is maintained through the *National Mental Health Policy*, the *Mental Health Statement of Rights and Responsibilities*, the *Second National Mental Health Plan*, 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*, the *National Action Plan for Depression*, as well as other documents under the national framework of the Strategy.

The aims of the renewed Strategy complement the aims of the initial Strategy, and are achieved under the themes of the *Second National Mental Health Plan* (promotion/prevention, quality and effectiveness of service delivery, and development of partnerships in service reform). Commonwealth funding to State/Territory governments is considered through broader renegotiations of the *Australian Health Care Agreements*.

## Consumer and Carer Participation

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:

Either voluntary or paid participation by consumers and carers in formal or informal planning, delivery, implementation, and evaluation of all activities associated with mental health services, as well as in all processes which effect the lives of consumers and carers, through sharing of information, opinions, and decision making power.

The aim of consumer and carer participation is to provide a process 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.***

Consumer and carer participation in determining mental health priorities ensures a sound basis for successful processes, programs and services to maintain and improve the mental health for all Australians.

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.

## • 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/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 recognizes 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.
  - Consumers and carers must be aware that responsibilities are associated with participation, primarily the active contribution to quality improvement processes.

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

- strategic planning for the organisation;
- service planning;
- 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/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).

## Best Practice Principles for Inclusion in Participation Policy

The following best practice principles have been identified as necessary considerations in the development of a consumer and carer participation policy, and are presented as a standard benchmark for mental health organisations to aim for when promoting and practicing consumer and carer participation.

<b>Practice 1</b>	All public, private, and non-government mental health systems will promote, through practice, consumer and carer participation in all processes that affect the lives of consumers and carers, for instance, recruitment, resource allocation, planning, service delivery, research, evaluation, and continuous quality improvement processes including accreditation against the <i>National Standards for Mental Health Services</i> .
<b>Practice 2</b>	All public, private, and non-government mental health organisations will engage consumers and carers with special expertise to participate in all processes and activities that affect the lives of consumers and carers. 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.
<b>Practice 3</b>	Consumers and carers will be employed by external agencies, such as, but not limited to, accrediting agencies, as people who have special expertise, to participate in all processes and activities that affect their lives (consumer consultant model).
<b>Practice 4</b>	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 policy template to suit individual needs and is 'locally owned'.
<b>Practice 5</b>	Each State/Territory will have a recognised peak mental health body representing that State/Territory, with consumers and carers involved in the management and operation of the organisation, and which operates for the benefit of people with mental illness and carers.
<b>Practice 6</b>	When considering consumer and carer participation, the selection process will ensure potential applicants are sought from key consumer and carer groups who are able to provide support and a network for consultation, for example, local, State/Territory, national, public, private, and non-government peak bodies.
<b>Practice 7</b>	Consumer and carer representatives at committees / forums, have the responsibility to <b>actively</b> participate in the discussions, decision-making and activities of that committee, and ensure the views of the body they are representing are adequately portrayed. In addition, consumer and carer representatives have a responsibility to report back, either verbally or written, to the body they are representing on the outcomes of their representation.
<b>Practice 8</b>	Terms of Reference and Duty Statements will be developed for consumer and carer representation and participation at all committees. This will ensure clarity and transparency in the roles and responsibilities of all positions.



<b>Practice 9</b>	Unless otherwise agreed by consumers and carers, consumers and carers will receive payment for their representative participation <sup>5</sup> 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.
<b>Practice 10</b>	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. For instance, satisfaction and evaluation surveys; focus groups; support groups; regular meetings with local, State/Territory, 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.
<b>Practice 11</b>	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 <i>National Standards for Mental Health Services</i> . Following the review process, where required, policies and practices will be changed to reflect the outcomes of the evaluation.
<b>Practice 12</b>	Consumers and carers with special expertise will participate in staff education/orientation activities in all public, private, and non-government mental health organisations.
<b>Practice 13</b>	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/contributors in all processes that affect their lives, including the planning, development, implementation, and evaluation of mental health services.
<b>Practice 14</b>	All public, private, and non-government mental health organisations promoting and practicing consumer and carer participation will maintain a database of consumers and carers available for participation once consumers and carers have agreed to have their details recorded on a database. Such a database will ensure a broad network of consumers and carers who are easily contactable and readily available to participate.

<sup>5</sup> 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.

- **CHECKLIST**

**Does the consumer and carer participation policy:**

- ✓ State a clear purpose?
- ✓ Have a set of principles that reflect the value the organisation places on consumer and carer participation?

Articulate the organisation's position in relation to consumer and carer participation in:

- ✓ Strategic planning for the organisation
- ✓ Service planning
- ✓ Service delivery
- ✓ Service implementation
- ✓ Service evaluation
- ✓ Health decision-making
- ✓ Resource allocation and development
- ✓ Other
- ✓ State responsibilities of all parties in implementing the policy?
- ✓ State what measures will be taken to monitor the policy's implementation?
- ✓ State whether / when the policy should be revised and evaluated?
- ✓ State how the policy will be evaluated (including consideration of what measures or indicators may be used in the evaluation)?
- ✓ Ensures the service promotes consumer and carer participation in all processes that affect the lives of consumers and carers?

Includes consumers and carers in every process that affects their lives, for instance:

- ✓ Recruitment
- ✓ Workforce
- ✓ Resource allocation
- ✓ Evaluation

- ✓Planning
- ✓Service delivery
- ✓Research
- ✓Evaluation
- ✓Other
- ✓ 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 to reporting mechanisms, either written or verbal, upon completion of their representation?
- ✓ Adopt the principles and practices outlined in the National Consumer and Carer Participation Policy Template and adopt them to suit local need?
- ✓ If 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 for 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/orientation activities within the organisation?
- ✓ Ensure the organisation provides ongoing support, education and training for consumers and carers on their rights and responsibilities and in 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?
- ✓ Ensure a database is maintained of consumers and carers available for participation?