



Mental Health
Coordinating Council

**Community Engagement Framework Policy
Draft NSW Health Policy Statement – V1**

October 2010

**Mental Health Coordinating Council
Broughton Hall
Bld 125 Cr Church & Glover St
Lilyfield NSW 2040**

For any further information please contact:

**Jenna Bateman
Chief Executive Officer
E: jenna@mhcc.org.au
Tel: (02) 9555 8388 ext 102**

**Corinne Henderson
Senior Policy Officer
E: corinne@mhcc.org.au
Tel: (02) 9555 8388 ext 101**



October 2010

The Mental Health Coordinating Council thanks the NSW Department of Health for providing us with an opportunity to input into the Community Engagement Framework Policy Directive: Draft Policy Statement -Version 1.

Purpose

MHCC propose that the specific purpose of the policy directive: "*Community Engagement*" be substantially strengthened. Whilst NSW Health states that "*community engagement activities have been conducted in the NSW health system for some time.... and that this framework builds on these structures, processes and knowledge to make CE core to planning and delivery of services,*" the considerable literature shows that although recognised as a fundamental component of policy development and service delivery in the Australian health sector (Gregory, 2007) ⁱ there is little evaluation of 'consumer' engagement - the extent or outcomes. Evaluations that do exist tend to be descriptive rather than focusing on how engagement ultimately influenced decisions (Gregory, 2008).

Building knowledge to ensure involvement must include meaningful reporting on the outcomes to the community to be factored into operational decision making processes. Without this information it will be hard to "*strengthen the capacity of NSW Health and communities to undertake community engagement activities.*"

The Framework **Overview** states that: "*Some health care providers fear that involving communities in planning and operations will result in loss of control over processes and outcomes. However community engagement does not mean that everyone has equal say in every aspect of decision-making –but rather upon mutually agreed areas that recognise the value each participant brings to the table*" (Framework, p. 4).

We suggest that this statement underlined (in the document) defines the inequality in the partnership between community and government that has long undermined the capacity to strengthen engagement. This begs the question as to how mutually agreed areas of participation are determined, and what governance arrangements are in place to support the determination.

Until a more equal relationship is established the problem will perpetuate. Similarly, whilst acknowledging that traditional power relationships "*can block certain individuals and groups,*" and stating in the key principles the importance of taking an active role and identifying inclusiveness; the principles are weakened by the comment that: "*the community should be involved in determining the purpose of healthcare services and policies and where their views and opinions count toward decision making,*" expresses a similar continuance of inequality and dismissiveness.

We suggest that it is necessary to include in the "*Purpose*" a statement as to the importance of community engagement because as Gregory: 2008, ⁱⁱ and Ridley and Jones: 2002 ⁱⁱⁱ suggest, it is:

- An ethical and democratic right
- A way of adding legitimacy to decision making
- A way of improving health outcomes and policy outcomes
- A way of improving relationships with consumers
- A way of serving political and democratic processes

Terms in the policy directive

MHCC note that the term community is used: “as a collective word that recognises the many ways in which groups of individuals are defined. For instance, a person may be defined as a patient, a carer or consumer while simultaneously belonging to particular groups in the community that in turn are defined by other shared characteristics and interests, such as gender, geographic location, profession or culture. Individuals are members of many groups and as a result able to represent a variety of interests”.

We suggest that this presents some difficulty particularly for the mental health sector that tends to refer to ‘consumer engagement’ rather than the use of ‘community’.

“Within health, there is no shared language about consumer engagement practice,”
(AIHPS, 2008, p.3).

MHCC propose that in defining some of the terms used in the policy directive, that the difficulty with regards to language and terminology described in the AIHPS study conducted in (2008)^{iv} is articulated so that those using the directive understand the problems that they may possibly encounter.

As the AIHPS has found, there is no consensus about the language and terminology that should be used to describe consumer or community engagement. Terms such as ‘consumer’, ‘community’, ‘citizen’, ‘participation’, ‘involvement’ and ‘engagement’ are frequently used, but without clear or common definitions. “Terms such as ‘consultation’, ‘involvement’ and ‘engagement’ are often used interchangeably, although they mean different things to different people.” (Health Canada, 2001; Sicmes, 2003).^v

Whilst this has been defined as an all-inclusive term in the policy document, it is quite vague in recognising the different engagement that may be necessary for different groups and individuals.

In addition to those terms defined, we propose that language in the policy directive better reflects the intention to engage broadly with consumers, carers, the community, consumer and community managed service delivery organisations and peak bodies. Examples from the AIHPS Glossary worth consideration are attached as an appendix to this submission.

Key Principles

The key principles in the document do not articulate a strong message of commitment. The NSW Health Department needs to make a commitment to putting what matters most to consumers /community at the centre of its work. The language used fails to instil a feeling of commitment by using terms such as: recognising, valuing, remaining open, fostering , building, involving, etc., rather than stating what it ‘will do’ or target; accountability, transparency and leadership. Mostly there is little ‘call to account’ on any matter of community engagement.

MHCC propose principles that express ideas in ways such as:

The NSW Health Department is committed to involving consumers and the community in its work, and sees the experiences, knowledge, wisdom and perceptions of consumers and the community as essential to its work to improve service delivery.

Acknowledge that a number of different methods of engagement will be required.

Believes that system, policy and program drivers that promote the adoption of consumer / community focused strategies need to be identified and encouraged.

Acknowledge the long history of consumer engagement in health that has been driven by consumers and consumer organisations; recognises the need to incorporate knowledge from this history and experience and actively support stakeholders' work in this area.^{vi}

Mandatory Requirements

1.2 Role of engagement structures and processes

To be added to engagement structures and processes enabling participation listed:

- Service governance
- Staff recruitment, orientation and training

1.3 Representation

We propose that in order to facilitate representation that people need to be paid sitting fees to participate.

We suggest that detail need to be included that refer to **processes for appointments** and **tenure** in the policy directive.

It is also necessary to address issues of **conflict of interest** with regards to employment and personal perspectives, and how they will be addressed.

1.5 Publicise structures and processes for participation

We propose that much broader avenues be sought to publicise engagement structures than Annual Report and NSW Health Website. Information could be disseminated through peak bodies and consumer organisations.

1.6 Consultation

We propose that sufficient time be given to consultative processes that require written responses, bearing in mind that respondents have other responsibilities. No less than one month should be given for any written response, but bearing in mind the length and complexity of some of the documents circulated, longer closing dates may be necessary.

1.9 Monitoring and Evaluation

It is important that quality management audit / accountability processes are in place that follow-up deficiencies identified in monitoring and evaluation. The evaluation processes described do not talk about accountability.

2.1 Education and Training

Communities should be supported to participate in education and training to better engage in consultative processes with consideration as to the costs involved, i.e. travel, carer support as well as remuneration.

2.3 Resources for participation

Ditto – 1.3

Implementation

The document states that 'community engagement occurs within the four levels of management where health services are planned and administered'. We propose that involvement at a strategic level is also included as a fifth level.

Ministerial Committees

Section 2.2 of the Framework identifies special advisory committees on particular aspects of health care. Mental Health and Justice Health are largely absent in the draft policy directive and framework document.

MHCC acknowledge that on page 19 - **People living with a chronic illness including mental health condition** are identified: *"There are unique factors that need to be considered in seeking the participation of people with psychiatric disabilities. Community organisations and self-help groups are a vital local and state-wide resource. Cooperation and joint decision-making is the key."* However, this statement fails to explain how community engagement in mental health services will take place. If this is explained in other Policy Directives it needs to be stated as a reference in this directive.

Mental health is identified under **Stream, department, program or service level** (p.21), but Justice Health and the Ambulance Service is only mentioned under **Network and state-wide services** (p.22) stating only that the community will be engaged at a broader level of decision making policies and operational procedures.

Carer/ attendant care

The expenses referred to do not include payment for a carer to accompany a representative, who may well have to pay a carer for their services otherwise not required. Whereas expenses for reimbursement of child-care and respite expenses are recognised.

Conferences and training

Once again the expectation is that community representatives will only receive associated expenses and not remuneration. Since public servants attend these opportunities as part of their work, it seems unjust that community representatives should have to pay for themselves to participate in activities necessary for them to undertake their role.

Identifying and locating groups in the community

We propose that under the heading State-wide community agencies that peak bodies for the different areas of health and disability be identified specifically.

MHCC thank the NSW Department of Health for their interest and express our willingness to participate in any future consultations.

Yours sincerely,



Jenna Bateman
Chief Executive Officer

ⁱ Gregory, J (2007). *Conceptualising consumer engagement: A review of the literature*. Australian Institute of Health Policy Studies, Melbourne.
http://healthpolicystudies.org.au/component/option,com_docman/task,cat_view/gid,92/Itemid,145/

ⁱⁱ Ibid.

ⁱⁱⁱ Ridley, J & Jones, L (2002). *User and Public Involvement in Health Services: A Literature Review*. Partners in Charge, SHS Trust, Edinburgh, Scotland. ISBN 1899751122
<http://www.sehd.scot.nhs.uk/involvingpeople/A%20literature%20review.pdf>

^{iv} Gregory, J (2008). *Engaging Consumers in discussion about Australian Health Policy: Emerging key themes*. Australian Institute of Health Policy Studies, Melbourne.
http://healthpolicystudies.org.au/component/option,com_docman/task,cat_view/gid,92/Itemid,145/

^v Health Canada (2000). *Health Canada Policy Toolkit for Public Involvement in Decision Making*. Health Canada, Ottawa, viewed 6 October 2008, http://www.hc-sc.gc.ca/ahcasc/alt_formats/pacrb-dgapcr/pdf/public-consult/2000decision-eng.pdf

Glossary

Carers are families and friends providing unpaid care to consumers.

Citizen engagement is a process that:

- Involves citizens, not just the public as represented by associations, health professionals, lobbyists and interest groups, in policy formulation, priority- setting and program delivery is a key component of “governance,” namely the process and traditions that determine how a society steers itself and how citizens are accorded a voice on issues of public concern, and how decisions are made on these issues
- Builds on, complements and generally moves beyond information distribution and consultation practices. It does not replace “traditional” consultation with stakeholder organizations, nor does it replace citizens’ role in the broader democratic process. Its purpose is to provide new opportunities to bring interested parties together as civic-minded individuals concerned about health issues. (Health Canada, 2000).

Community means a group of people with something in common, such as people who live in the same neighbourhood, suburb or town or with a shared interest such as in the development of an accessible, effective and efficient health service that best meets their needs.

Community organisations are organisations that represent groups with particular shared interests within the community.

Consumers are users, or potential users of health services, including children, women and men, people living with a disability, people from diverse cultural and religious experiences, socioeconomic status and social circumstances, sexual orientations, health and illness conditions.

Deliberative techniques are techniques which provide participants with an opportunity to reflect, discuss, question and think. They involve participants considering facts and issues from multiple points of view, and discussion and other techniques which build participants’ knowledge and expand their understanding. They typically involve greater engagement.

Engagement is an informed dialogue between an organisation and consumers, carers and the community which encourages participants to share ideas or options and undertake collaborative decision making, sometimes as partners (Health Canada).

Health consumer organisations are organisations that represent health consumers generally, and/or particular groups of health consumers.

Respondent means an individual or organisation who participated in the consultation process through making a submission or attending a consultation meeting.

Involvement is the process of involving consumers, carers and community members in planning and decision making.

Participation occurs when consumers, carers and community members are meaningfully involved in decision making about health policy and planning, care and treatment, and the wellbeing of themselves and the community.

Patient-centred care involves providing care that is respectful of and responsive to individual patient preferences, needs and values and ensuring patient values guide all clinical decisions. It means a partnership between the consumer and the health provider and applies to all settings of care (Committee on Quality Health Care in America, 2001).

Representative is a consumer, carer or community member who is nominated by and accountable to an organisation of consumers, carers or community members.

Note: definitions of carers, consumers and participation are drawn from: *Doing it with us not for us*, Department of Human Services, 2006). Source: Australian Commission on Safety and Quality in Health Care. (2008). *Development of a consumer engagement statement for the Commission: Consultation Report*.