

MH-CoPES

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The MH-CoPES Project is to develop or identify an instrument or process to collect, collate, measure and report consumer perceptions and experiences of mental health services. The instrument or process will be appropriate, effective and efficient; and reflective of recent trends in health related surveys and other methodologies available to elicit information relating to experiences of service users.

At the end of the project, a full tool kit will be available to ascertain consumer perceptions and experiences of each of the following aspects of mental health service delivery:

- Availability of services;
- Access to services;
- Getting information;
- Treatment and assistance;
- Staff;
- Participation; and
- Hospital care;

that would enable both quantitative and qualitative measurement and assessment.

MH-CoPES is a partnership between the NSW Centre for Mental Health and NSW CAG. The project will utilise the expertise within the NSW Centre for Mental Health to provide guidance and facilitate access to services and stakeholder groups. NSW CAG will provide line management and administration functions. The Working Group (TWG) will oversee the progress of the project and report back to stakeholder groups and associated committees.

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The Mental Health Consumers' Perceptions and Experience of Services Project (MH-CoPES) is a partnership between The NSW Centre for Mental Health and NSW CAG. In this presentation, we will introduce the MH-CoPES project, outlining why and how it was developed, and what the project aims to achieve. We will then explore the implications of MH-CoPES for mental health services – both government and non-government, and finish reflecting on the value of consumer participation in the project and beyond.

Consumer participation in planning and implementing health services has increasingly been recognised as critical to effective, useful, health services (Goodare and Smith, 1995; National Resource Centre for Consumer Participation in Health, 2000). Within mental health, consumer participation in services is placed firmly on the Australian policy agenda (Australian Health Ministers, 2003). While participation itself is a diverse activity, one important component relates to consumers views of, and experiences with, services being heard and valued, and further, being used to guide quality improvement within services (Phillip & Stewart, 1999; Wadsworth & Epstein, 1996). Currently, NSW Mental Health Services do not have any statewide process in place to determine consumer perceptions and experiences with services. It is this gap that the MH-CoPES Project aims to fill.

The concept of the MH-CoPES Project developed out of discussion at the MHOAT Consumer Consultative Committee, which meets quarterly at the Centre for Mental Health. The MHOAT CCC was established in early 2001 to provide consumers with a forum to discuss implementation issues associated with the Mental Health Outcomes Assessment Project (MHOAT) (NSW Health

Department, 2001), share experiences, and discuss consumer views of services. From these discussions, in 2002, a submission to the NSW Minister of Health was made, for funding of the MH-CoPES Project (NSW Consumer Advisory Group – Mental Health, 2002).

In 2003, a Technical Working Group (TWG) for the project was established. Eight mental health consumers, 3 mental health professionals, as well as a representative from the NSW Centre for Mental Health, and an expert in evaluation sit on the TWG. Eight areas from across NSW are represented on the TWG. In January this year, the Project Officer was employed. Phil will discuss the role of the TWG later in this presentation, while exploring the value of consumer participation in the project.

MH-CoPES Aims and Objectives

The overall aim of the project is to identify or develop an instrument and process to collect, collate, measure, and report consumer perceptions and experiences of mental health services. The instrument and process must be appropriate, effective, and efficient. In achieving this aim, we have the following objectives:

1. To identify principles underpinning successful and effective reporting of reliable data on consumers' perceptions and experiences with services; and
2. To produce a full tool kit which can be used to ascertain consumers' perceptions and experiences of services, with specific attention to the following aspects of service delivery:
 - a. availability of services;

- b. access to services;
- c. getting information;
- d. treatment and assistance;
- e. staff;
- f. participation; and
- g. hospital care.

The key activities we will be engaged in to achieve our aims include:

1. defining clear criteria to evaluate existing tools, and/or develop a new tool;
2. conducting a literature review on measures, methods, tools etc.;
3. identifying existing tools in use;
4. evaluating the tools identified;
5. producing an interim report for key stakeholders on outcomes of the evaluation (4);
6. obtaining feedback from key stakeholders;
7. modifying tools based on stakeholder feedback, draft report;
8. Holding a state-wide targeted workshop to comment on the proposed tool/s; and
9. producing a final report.

While some of these key activities will occur sequentially, many will be occurring in parallel. Currently, we are actively working towards activities 1 and 2, and are in planning for 3. Throughout this research process, we will be engaging in consultation and collaboration with a range of key stakeholder groups, as well as evaluating the project itself.

Implications of MH-CoPES for mental health services (both government and non government organizations).

There is increasingly recognition of the need for integration of government and non-government service provision within the mental health field (Australian Health Ministers, 2003). We believe MH-CoPES has a range of implications for both government and non-government mental health services, as well as for consumers of any of these services. For services we see these implications including:

- A new and useful mechanism to guide and track service change, which is based on consumers' views of what they need in their recovery;
- Services will have a “grassroots” idea of what’s working and what needs to change or be improved;
- The tool and process will provide useful information to aide in audit, review, and accreditation processes; and
- Knowledge of what is working for consumers in the service will be produced. This information is as important as the information that suggests areas for improvement.

For NGOs, using the tool and process recommended by MH-CoPES will provide these benefits, additionally, this will provide a mechanism to aid the continuity and linking between government services and NGOs, a benefit for everyone involved in mental health care: providers and consumers.

As well as the benefits for services, we see implications of MH-CoPES for consumers including:

- Means to make a difference in services;
- Be taken seriously and be heard;

- Empowerment;
- A mechanism to track changes in their own views of services, of their outcomes and needs; and
- Improved services.

Exploring the Value of Consumer Participation in MH-CoPES and Beyond

Firstly, I believe that this issue needs to be considered within the national and state policy framework. It is policy for consumers to participate meaningfully in the planning and evaluation of services. This has been established in policy documents such as the National Mental Health Standards (1996), the National Practice Standards for the Mental Health Workforce (Commonwealth Dept. of Health and Ageing, 2002), and the 3rd National Mental Health Plan (Australian Health Ministers, 2003). Within this context, what are the benefits for MH-CoPES in having consumers involved on the TWG?

I see consumer involvement contributing in a range of ways, which include:

1. Consumer involvement to monitor process and nature of research.

It is important that research be conducted in a “consumer-friendly” manner, and further, research should be conducted “by and with” consumers, rather than “for” consumers. Consumers should be involved in the research process, particularly contributing ideas regarding the methods used, and the ethics of research, as well as issues of confidentiality and privacy, the types of questions asked, and the manner in which they are asked. In MH-CoPES,

consumers from the TWG provide support to the Project Officer, and help with setting goals, timelines, process issues, and with implementation.

2. Connecting with consumer networks.

One of the main aims MH-CoPES has is that whatever tool and process we recommend, it will be seen as appropriate and useful by consumers across the state. Consumers on the TWG can consult and get input from a large range of consumers and consumer organizations, thus providing a link to, and ensuring, broader consumer input throughout the project. The TWG members are able to explain the project and its goal of improving mental health services, assisting to promote the possible benefits to other consumers. In addition, through their own networks, they can help with piloting when we reach that stage.

3. Bring lived experience.

Consumers have direct experiences of being in hospital, being treated in the community, as well as our experiences of discrimination, poor staff attitudes, and gaps in the system. The lived experience brought by the consumers on the MH-CoPES TWG will be essential to the outcome of the project, and cannot be achieved without consumer participation.

4. Legitimise project from consumer perspective.

Consumers have been involved in MH-CoPES from the start. The project is also a collaboration between both consumers and other people involved in the mental health field, however, it is governed and managed by a TWG, which involved a majority of consumers, and the NSW Consumer Advisory Group, a consumer and carer organization. When a project is focusing on the area of mental health, and collecting data from consumers, the project must have

consumers involved at the management and decision-making levels to retain its credibility, legitimacy and focus. As the National Resource Centre for Consumer Participation in Health (2000, p. 7) state: “in order to create effective change, service providers [and researchers] need to move beyond seeking feedback to engaging with consumers, planning with consumers, acting with consumers and evaluating with consumers.” MH-CoPES is not only attempting to produce a tool and process which services can use to achieve this, but is also aiming to conduct the research project in this manner.

Additionally, Taylor and Clarke (1993; cited in National Resource Centre for Participation in Health, 2000. p. 7) state “since patient treatment and care is the major outcome of any health service, no definitive statements can be made about the quality of the service unless patients have been asked about that service”

Now I want to briefly touch on some issues about consumer participation beyond MH-CoPES, and how I see MH-CoPES articulating with this broader mental health context.

MH-CoPES has implications for further development of partnerships within the mental health field. Partnership is one of the very real forms of participation. Partnership is not manipulation, therapy, informing or placation. A partnership occurs when power is shared in an ongoing way: power between services and consumers; researchers and consumers. I see consumer participation through the TWG, and consultations that will occur with consumers throughout the project providing another, important setting where consumers will engage in genuine partnership with both mental health researchers, and services.

Finally, and in summary, by consumer participation the project will be guided by consumer needs. I believe the tool/s and process that MH-CoPES recommends at the end of the next 18 months, will contribute to improving consumer outcomes.

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