



MH-CoPES

Measuring and Responding to Consumer Perceptions and Experiences of Adult Mental Health Services



Stage 2

Response to Discussion Paper: Introducing MH-CoPES Stage 2: Developing the Framework for Consumer Evaluation in Service Improvement

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1. Introduction

The Mental Health Consumer Perceptions and Experiences of Services (MH-CoPES) project aims to develop a framework for consumer evaluation of mental health services. Stage 1 was successfully completed by NSW Consumer Advisory Group – Mental Health Inc. (NSW CAG) in conjunction with NSW Centre for Mental Health (CMH) in 2005. This resulted in the development of a draft MH-CoPES Framework for Consumer Evaluation of Mental Health Services (MHS) and the MH-CoPES Questionnaires. At the conclusion of Stage 1 different viewpoints existed between consumers, service providers, service management, Area Mental Health Services (AMHS) and the NSW Department of Health (Department of Health) as to the role and place of consumer evaluation in AMHS through MH-CoPES. The Stage 1 Report recommended that further development of the MH-CoPES Framework be undertaken, including work to

“Clarify the role and place of consumer evaluation of mental health services through the MH-CoPES Framework for Consumer Evaluation in service improvement, and continue to build a united vision and partnership approach between the Centre for Mental Health, AHS [Area Health Service] mental health services and consumers, plus other stakeholders, for consumer evaluation through MH-CoPES.” (NSW Department of Health, 2006: p57; parentheses added).

This recommendation has been adopted as the first objective of the MH-CoPES Stage 2 project. Indeed, the success and sustainability of MH-CoPES depends upon the support and commitment of consumers, service providers and management, and the Department of Health. Further, the MH-CoPES Framework and any tools associated with it need to be seen as useful to all concerned.

A discussion paper introducing the MH-CoPES Stage 2 project was distributed to AHS Directors and a network of consumers, carers, service providers, staff and other key stakeholders. This paper aimed to commence the process of developing a consensus as to the role and place of MH-CoPES in service evaluation within AMHS. The paper sought the perspectives and requirements of each of the groups of stakeholders as a platform for ensuring that the needs of these groups are adequately met through the continued development of the MH-CoPES Framework.

2. Approach

The objectives of the discussion paper were to:

- Describe MH-CoPES, and
- Seek feedback about the role and place of consumer evaluation in AMHS through MH-CoPES.

The paper was written for people who use public, adult mental health services in NSW, and for people providing and managing those services, particularly for those in the two pilot sites (North Ryde – Macquarie Hospital and Ryde Mental Health Community Services (Northern Sydney Central Coast AHS), and Orange – Bloomfield Hospital and Orange Mental Health Community Services (Greater Western AHS)), as well as for the Department of Health. Questions guiding responses were provided, however all comments on any of the issues raised in the paper were welcomed. Responses to the discussion paper were initially sought by Friday 1st December 2006; however this timeframe was extended until Friday 15th December 2006.

The discussion paper was distributed in November 2006 along with *A statewide approach to measuring and responding to consumer perceptions and experiences of adult mental health services. A report on stage one of the development of the MH-CoPES framework and questionnaires* (NSW Department of Health), prepared by NSW CAG. The paper and report were sent to AHS Directors, all members of the Technical Working Group from MH-CoPES Stage 1 and all stakeholders from Stage 1 who had requested to be updated on the project. In addition the MH-CoPES representatives from Orange and North Ryde were each sent 100 discussion papers for distribution to service staff, AMHS staff, consumers, carers and other stakeholders within the pilot sites. Over 350 discussion papers were circulated.

3. Respondents

A total of 18 responses were received to the discussion paper. Who respondents were is detailed in Table 1.

Table 1: Respondents to the Discussion Paper

| Identification of Respondents | Number of Respondents | AHS* |
|---|-----------------------|--------------------------------------|
| Consumer | 1 | NCAHS |
| Consumer & Carer | 1 | |
| Consumer & Staff Member/Service Provider | 2 | SESAHS (1) |
| Consumer, Carer & Staff Member/Service Provider | 2 | GWAHS (1) SSWAHS (1) |
| Carer | 2 | |
| Carer & Staff Member/Service Provider | 4 | SWAHS (2) GWAHS (1) SSWAHS (1) |
| Staff Member/Service Provider | 2 | HNEAHS (1) |
| Other | 4 | |
| TOTAL | 18 | |

* Optional field completed by 9 respondents

NCAHS = North Coast Area Health Service

SESAHS = South Eastern Sydney Illawarra Area Health Service

GWAHS = Greater Western Area Health Service

SWAHS = Sydney West Area Health Service

SSWAHS = Sydney South West Area Health Service

HNEAHS = Hunter New England Area Health Service

Of those who identified as “other”, responses were received people involved with the Consumer Participation Strategy, General Practitioners, the Official Visitors (OV) Program and a non-government organisation (NGO).

4. Responses and Discussion

4.1 General Discussion of Responses

Respondents agreed with the aims and objectives and the definition of consumer evaluation adopted by MH-CoPES. This is valuable feedback as it helps ensure that the Framework that is being developed fits with the views of consumers, carers, MHS staff, and service providers. This feedback also provides insight into the role and place of MH-CoPES in service improvement, as discussed below.

Some respondents proposed additional objectives for MH-CoPES. These included:

- The “provision of opportunities for consumers to promote and provide information about MH-CoPES to the wider community” (carer/staff member/service provider);
- “A clear pathway of action/change should concerns arise” (consumer/carer/staff member/service provider);
- “Continual involvement of consumers at every level of Stage 4 (of the Framework) is essential” (OV program respondent; parentheses added); and
- That MH-CoPES is “...not just about evaluation – it’s about perceptions and experiences” (consumer/carer/staff member/service provider).

These suggestions are not inconsistent with the current objectives and principles of MH-CoPES. The involvement of consumers throughout the four stages of the MH-CoPES Framework will enable consumers the opportunity to promote and provide information about MH-CoPES. Further, the involvement of consumers in Action and Change and the development of protocols for this stage of the Framework will be developed and encompassed throughout Stage 2.

Consensus was reached that it is important that alternatives to a Questionnaire be available for consumers to provide feedback. This

supported the recommendations from the Stage 1 Report (NSW Department of Health, 2006) and one of the sub-goals of objective 2 of MH-CoPES Stage 2. During Stage 2, a literature review and consultations will be conducted to determine the alternative options to a Questionnaire that need to be developed. The suggestion of using the internet for collecting feedback was made by a respondent, and also arose in Stage 1 (NSW Department of Health, 2006). Although it is not within the scope of MH-CoPES Stage 2 to investigate the possibilities and implications of such an option, it is an option that requires further investigation and development in future projects.

The recommendations of Stage 1 were that “due to privacy concerns, ideally, clinical staff should not be involved in distributing, collecting or return of consumers’ feedback” (NSW Department of Health, 2006: p43). Respondents’ views differed, however, as to whether this is an important factor for MH-CoPES. All respondents identifying as consumers expressed this as important, with variation in views between non-consumers. In addition, there was disagreement as to whether consumer consultants should be distributing the MH-CoPES Questionnaires. These highlight areas of disagreement between stakeholders as to how MH-CoPES should be implemented and conducted. Various methods for distributing the Questionnaire, including the Questionnaire being handed out by a consumer, or by staff not directly involved in clinical care were suggested in Stage 1 and will be trialled in Stage 2. The question as to who should distribute the Questionnaire should be resolved during MH-CoPES Stage 2 through consultations and the examination of the impact of various means of distributing the Questionnaire on responses in the trial.

A majority of respondents felt that Data Analysis should be undertaken by one central body. There were however conflicting views as to whether this body should be independent of the mental health system. This issue will be considered further during consultations in Stage 2.

It was generally viewed that the three points of Reporting and Feedback and the five points of Action and Change detailed in the discussion paper are

considered important. This reflected the findings from the Stage 1 Report (NSW Department of Health, 2006). Of note, the majority of respondents viewed it important that individual reports be provided to each service unit. This has implications for how the feedback is collected. The draft Questionnaires from Stage 1 (NSW Department of Health, 2006), based on recommendations from consultations, indicate only the Area Mental Health Service of the service used by the consumer. In order to provide reports to individual services it is necessary for the name of the service unit to be identified on the Questionnaire. This will be trialled in Stage 2.

A few additional issues and suggestions arose from responses to the discussion paper and will form the basis of consultations with stakeholders during Stage 2. These include:

- Whether consumers feel safe providing feedback about services; and
- The involvement of carers in MH-CoPES in areas such as Data Collection and Action and Change.

Responses to the discussion paper also raised cultural and change management issues that respondents identified as relevant to the future implementation and sustainability of MH-CoPES within the mental health system. These matters will feed into Objective 3 of MH-CoPES Stage 2 which will focus on understanding cultural and change management issues related to MH-CoPES. The issues identified by respondents are:

- How the sustainability of MH-CoPES will be managed;
- The definition of “consumer”, as relating to people using mental health services as opposed to prospective users of services, used and accepted by AMHS and consumers;
- The inclusion of the spiritual dimension in an holistic approach to recovery, treatment and participation;
- Limited employment of consumers within AMHS;
- Ramifications for consumers identifying issues with services – this is an issue of developing trust and an environment open to receiving feedback;

- Consumers' feedback being taken seriously; and
- The power imbalance between MHS and consumers.

There were additional issues that arose that are beyond the scope of the MH-CoPES Stage 2 project. These issues, indicated below, require further consultation and investigation through future projects:

- The development of an evaluation mechanism consistent with MH-CoPES for carers to provide their feedback about mental health services;
- The development of MH-CoPES to be suitable for use by Culturally and Linguistically Diverse persons and communities, including the Questionnaires being produced in community languages; and
- A mechanism for consumers to provide feedback about the services received from their GP who participates in their mental health care plan.

4.2 The Role and Place of the MH-CoPES Framework for Consumer Evaluation of Mental Health Services in Service Improvement

Respondents indicated that the definition of consumer evaluation as outlined in the discussion paper is consistent with their own definition. In brief, this definition considers that consumer evaluation of mental health services means the opportunity for consumers to:

- Participate in identifying strengths and weaknesses of their MHS;
- Have their say about what is working well in the service and how the service could improve from their perspective;
- Help assess what may need to change about the quality and delivery of services;
- Give feedback on things that matter about the quality and delivery of MHS based on their experience of the service; and
- Participate in improving services through generating solutions to problems identified and assisting with the implementation of solutions for change.

Consumer evaluation must also emphasise the evaluation of services from the perspective of the consumer, and not the perspective of the service provider or others involved in service provision. Some comments from respondents were that consumer evaluation is “to identify consumer problems, difficulties as they see it and identify with it and not what the mental health service providers see as consumers problems” (consumer/carer) and to “increase visibility; raise profile and validity of consumer-identified issues” (OV Program respondent). It is essential that the definition of consumer evaluation outlined be the central focus upon which MH-CoPES is based and conducted.

From the responses received to the discussion paper there is agreement that MH-CoPES should encompass the objectives of:

- Improving dialogue and partnership between consumers and the mental health service;
- Providing regular opportunities for consumers to express their perception and experiences of mental health services; and
- Providing opportunities for participation in service evaluation processes.

As with the definition of consumer evaluation adopted by MH-CoPES, these objectives provide the basis of MH-CoPES. Combined, they also provide a clear purpose and aim of MH-CoPES.

It is evident that the perceived role of MH-CoPES is to provide genuine opportunities for consumer participation in evaluating mental health services. It is also to ensure that continuous quality and service improvement is embedded within mental health services and the mental health system. Such improvements must be based on the feedback, perceptions and experiences of consumers. Respondents re-iterated the importance of MH-CoPES in providing a voice for consumers, and through this, empowering consumers.

Several respondents indicated that it is imperative that consumers be involved in each of the four stages of the MH-CoPES Framework, and in the administration of MH-CoPES. Although there was not agreement on the issue, some respondents thought it very important that consumers be involved in the distribution of the Questionnaire. Some suggested that Data Analysis should be conducted by an independent and consumer led body, while others suggested that all stages of the Framework need to be consumer led. Indeed, having consumers involved in and lead the processes of MH-CoPES will provide further opportunities for consumer participation in service evaluation, and further empower consumers.

Consumer participation in service evaluation is identified nationally and internationally as a priority and is essential to both the quality improvement of MHS and the improvement in peoples' health (NSW Department of Health, 2006). MH-CoPES needs to provide opportunities for consumer participation in service evaluation through consumers being involved not only in evaluating services from their perspectives, but also in the administration of each of the four stages of the MH-CoPES Framework. It is imperative for consumers to have the opportunities to participate in developing and implementing plans for action and change to improve services based on the feedback of consumers. Through continuous cycles of the MH-CoPES Framework, consumers will also be involved in the monitoring of service improvement.

It has been indicated through responses to the discussion paper that it is important that MH-CoPES is a process for improvement of services at a local level and not simply for evaluation and comparison between services. As suggested by an NGO, services should be evaluated independently with improvements monitored so that services are better meeting the needs of consumers. As such, MH-CoPES has a significant role in supporting MHS to be based on:

- Consumer participation;
- Empowerment of consumers;
- Recovery orientation;

- Accountability of services to consumers, families, carers, staff, funding bodies, AMHS and the NSW community;
- Continuous improvement; and
- A partnership and collaboration between consumers, service providers, staff, AMHS, and the Department of Health.

Respondents felt that one of the benefits of MH-CoPES is that it will provide a common and statewide Framework for consumer evaluation of mental health services across NSW. Respondents to the discussion paper indicated that MH-CoPES must be a collaboration and partnership between consumers, staff, MHS, AMHS, and the Department of Health. A model for the place of MH-CoPES within the mental health system needs to be established to enable such a partnership. Furthermore, these relationships need to be developed and maintained. They must be built upon a common goal of consumer participation in service evaluation and improvement, and upon the principles of empowerment, respect and equality. One respondent noted that from the outset discussions need to be held around new approaches within MHS as a means of building these relationships. This will facilitate the growth of dialogue and partnership between mental health services and consumers so that there is an agreed alliance in seeking and undertaking continual improvement through MH-CoPES.

Some responses were that the role of MH-CoPES is to achieve “systematic changes at local level” (consumer/carer/staff member/service provider) and “best practice and better outcomes for all parties in local areas of service delivery” (carer/staff member/service provider). These and other responses indicate that MH-CoPES needs to be owned at a local level by all stakeholders and that plans for service improvement and their implementation must be determined and owned at a local service level. Such ownership by all stakeholders is dependent upon a partnership, collaborative relationships and a common commitment to consumer participation in evaluating and improving services.

It was also indicated that the MH-CoPES Framework and its underlying values need to be mandated and supported at a state government level. This supported the recommendations from consultations during Stage 1 (NSW Department of Health, 2006). Indeed, the Centre for Mental Health, the Department of Health and Area Mental Health Services need to demonstrate a commitment to the MH-CoPES Framework and to continuous service improvement based on the experiences and feedback of consumers. Furthermore, respondents to the discussion paper stressed the importance of accountability of services to consumers for service improvement through MH-CoPES. For this to be achieved, it is essential that the MH-CoPES Framework and reporting processes be mandated by the Department of Health for MHS and AMHS in NSW.

Whether MH-CoPES or the analysis of consumers' feedback should be conducted by an independent body remains a debated issue. Some respondents indicated that independence was very important to the legitimacy of the MH-CoPES process. Other respondents, however, considered that independence is not important. This was a debated issue during Stage 1, with some feeling that MH-CoPES needed to be independently led to ensure that consumers' voices are respected and acted upon, and not lost to the views of the service. On the other hand, concern was expressed that MH-CoPES needs to be embedded within existing data mechanisms to ensure that consumers' feedback is communicated to services by an authority to whom it is accountable. Further consultation on this issue is required throughout MH-CoPES Stage 2.

4.3 Where to From Here?

The conclusions from the discussion paper are restricted by the small number of responses received. The limited response to the discussion paper provides an indication that such papers may not be the most effective mechanism for seeking input from concerned stakeholders, suggesting that other formats such as discussion groups and verbal consultations may be more effective.

Despite the limitations, the responses received are useful in that they provide an indication of the direction we should be taking in relation to the role and place of MH-CoPES in service improvement. The findings from this report build a basis for further consultations with consumers, carers, staff members, service providers, the statewide reference group and other key stakeholders throughout NSW during MH-CoPES Stage 2.

References

NSW Consumer Advisory Group (2006). *MH-CoPES: Measuring and responding to Consumer Perceptions and Experiences of Mental Health Services. Stage 2. Discussion paper: Introducing MH-CoPES Stage2: Developing the framework for consumer evaluation of mental health services*. Unpublished Paper.

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