



## **RESPONSE TO THE NSW CONSUMER ADVOCACY GROUP (CAG) DISCUSSION PAPER**

---

### **Introducing MH-CoPES Stage 2: Developing the Framework for Consumer Evaluation in Service Improvement**

**December 2006**

# Introduction

---

## ABOUT CARERS NSW

### Who we are

Carers NSW (CNSW) is the peak body representing 750,000 carers in this state. CNSW provides a range of services and supports for carers and the community, including :

- Education and training for carers, service providers and communities;
- Emotional support, counselling and individual advocacy for carers;
- Information, publications, resource development and delivery;
- Policy development, research and advocacy;
- Sector development and systemic change; and
- Service innovation, development and evaluation.

### Who we represent

Carers are usually family members who provide support to children or adults who have a mental illness, disability, chronic condition or who are frail aged. Carers can be parents, partners, brothers, sisters, friends or children of any age. Carers may care for a few hours a week or all day every day. Some carers are eligible for government benefits, while others are employed or have a private income.

## THE MH-CoPES PROJECT

CNSW understands that the Mental Health Consumer Perception and Experience of Services (MH-CoPES) project aims to develop a framework for consumer evaluation of mental health services. Our further understanding of the project is that :

- Stage 1 of the project has been successfully completed with the development of a draft MH-CoPES Framework for Consumer Evaluation of Mental Health Services, including the MH-CoPES Questionnaire.
- Stage 2 of the project comprises two streams: *Developing the Framework* and *Laying the Statewide Foundations*. *Laying the Statewide Foundations* is focusing on implementing a functioning process for the distribution, collection and reporting on the MH-CoPES Questionnaire throughout NSW. *Developing the Framework* aims to complete the development of the Framework and Questionnaire, which were produced in Stage 1. *Developing the Framework* will generate an agreed and fully articulated MH-CoPES Framework for Consumer Evaluation of Mental Health Services, suitable for implementation within public mental health services for adults throughout NSW.

## ABOUT THIS RESPONSE PAPER

CNSW is pleased to have the opportunity to comment on the Consumer Advocacy Group (CAG) Discussion Paper *Introducing MH-CoPES Stage 2: Developing the Framework for Consumer Evaluation in Service Improvement*.

As noted within the Stage 2 Discussion Paper, the support and commitment of a range of stakeholders is critical to the success of a consumer evaluation of mental health services initiative, such as MH-CoPES. Further, the Discussion Paper states that the different perspectives and requirements of these groups need to be understood and ideally consensus reached, so that the needs of these groups can be adequately met.

However, CNSW notes that carers are generally not included within the Discussion Paper and are not considered one of the stakeholders whose perspectives should be taken into account when developing an initiative that seeks to evaluate mental health services.

Since the vast majority of care for people with a mental illness/disorder occurs in the community, the role of the carer is recognised as pivotal to the consumer's management of and response to their illness.

It is also generally accepted that, where a consumer has a carer, inclusion of that person as part of the health care team can be beneficial for all parties involved.

Including carers within the Discussion Paper is not only important to provide consistent recognition of their role within the health care team but also to confirm that carers must have the opportunity to provide feedback on services and work with other stakeholders to effect change. Consumers and carers have different experiences of the health care system and this should be evaluated in order to achieve systemic improvement.

Accordingly, CNSW asserts that any evaluation system for mental health services needs to recognise :

- The role which carers play in helping the consumer to manage their mental illness/disorder and supporting their general health and well-being;
- The partnership that exists between carers and the person with a mental illness/disorder for whom they care;
- The importance of including carers in the health care team; and
- The benefits that can be gained from including carers in the evaluation process.

## The Role of Carers

---

Family and friends are increasingly providing a significant proportion of health care in the community, without pay and often with very limited support. Current trends in the health care system in Australia, including workforce shortages and the limited capacity of acute care systems which leads to early discharge from hospital, means there is greater reliance on carers than ever before.

While there are no reliable estimates on the number of people caring for someone with a mental illness or disorder, data collected through the Carers NSW carer support telephone line shows that approximately 10% of calls are from carers in this category. If this is indicative of the wider population, there could be around 75,000 carers of people with mental illness in NSW. ABS statistics also demonstrate that 12% of all people receiving some assistance from an informal provider report a mental disorder as their main health condition (this excludes behavioural and developmental disorders).

Caring for someone with a mental illness is a complex experience that requires significant commitment and understanding, and can involve a range of tasks and functions.

The role of a carer who supports a person with a mental illness/disorder involves many demands and challenges, from dealing with the emotional and physical needs of the person they support to interacting with often-fragmented health, mental health and welfare systems regarding access to services.

The carer then needs to balance these responsibilities of the caring role with their other family and work responsibilities, and their own individual needs.

### THE IMPACTS OF CARING

Caring is rarely planned for. As a result, carers are rarely prepared for their role.

Carers often say that because of their lack of knowledge they have to learn the best way to care by 'trial and error' and by seeking out information on their own initiative. Even when they have worked in a related profession (such as nursing, aged care or disability services), carers may still find the emotional aspects of caring for a relative or friend overwhelming and difficult.

Caring almost inevitably entails loss and grief (O'Shea, 1999) and may exacerbate pre-existing difficulties within a relationship. There are also significant health impacts for carers.

A national survey of carer health and wellbeing conducted by Carers Australia in 1999 noted the health impacts of caring includes physical injury, a general decline in physical health and the deterioration of mental and emotional health.

A significant proportion (55%) of respondents to the above survey also reported suffering from tiredness or exhaustion since taking on a caring role, with reasons for this cited as the constant pressure of caring; stress; disturbed or lost sleep; and providing 'mobility' for the person needing care (eg lifting or transferring).

These findings are supported by the ABS National Survey of Disability, Ageing and Carers in 2003, which notes that 34% of carers feel weary or lack energy and 29% are often worried or depressed. According to Women's Health Australia, (Lee, C and Porteous, J, 2002) carers are more likely to report overall health as 'fair' or 'poor' and to have been admitted to hospital in the past year.

In terms of injuries, soon to be released research findings of over 1600 carers in Australia found that injuries for carers were often focused in the back, shoulder and neck. Additionally, these findings noted the health issues developed since becoming a carer included orthopaedic or spinal problems, cardiovascular problems and emotional or mental problems.

Caring for a person with a mental illness can be even more difficult due to the unique features of the social context which influence the carer role in mental health, such as the stigma, guilt and isolation of mental illness and the intermittent periods of illness with fluctuating symptoms.

Caring can also last a long time and the negative impacts of caring may be ongoing, cumulative and spread over many years.

## **The Care Partnership**

---

When a person with a mental illness/disorder receives assessment, treatment or support from a public mental health service, it is usually beneficial if their family and friends become partners in a collaborative therapeutic relationship with professional mental health workers and the person with a mental illness. This partnership operates to assist the person's management and responses to their illness.

The word partnership implies equality between those involved – working together to achieve the same thing. In the context of caring for a person with a mental illness/disorder, such a partnership should involve carers, consumers and key staff, such as case managers, psychiatrists and other clinicians, acknowledging and respecting the skills and resources that all parties bring to the care team.

### **THE BENEFITS OF CARER INCLUSION**

While their caring role is generally accepted as paramount to the recovery and overall care and support of consumers, carers often feel that their knowledge and experience is not sufficiently acknowledged or used in health and care planning.

However, there is now considerable evidence that the inclusion of carers within the acute, community and primary health setting has a range of benefits, improving outcomes for consumers and reducing health care costs.

For mental health consumers, there is :

- increased compliance with treatment and discharge plans;
- the prevention of readmissions;
- improved family functioning;
- increased periods of wellness; and
- improved quality of life and social adjustment.

For mental health professionals, there is valuable information and feedback, which can contribute to effective planning and management.

For example, carers often have detailed and significant information or advice that can have an impact on the proposed treatment plan – particularly when the consumer may have a limited capacity to provide input themselves. Without taking this information into account, treatment and discharge plans for the consumer may ultimately be flawed, resulting in non-compliance and possible readmission.

### **WHY CARERS ARE OFTEN NOT INCLUDED**

Although there is a move within the mental health system towards involving carers as 'partners in care', there are still many reasons why they are not included and do not receive recognition of their important role. This may relate to the ethical and legal obligations of mental health professionals regarding confidentiality and the need for consumers to provide 'informed consent' prior to the health team being able to share information about the consumer.

In many cases, mental health professionals are also concerned that involving carers more fully will take away from their ability to focus their time and energy solely on the consumer – who they perceive to be their only client.

Additionally, members of the mental health team may never have received training in how to deal with complex issues, such as confidentiality, and how to address the different needs of the consumer and the carer. Because of this, they lack confidence and so avoid giving any information, often citing confidentiality as the reason.

Not only does this leave many carers battling for information and advice about the person for whom they are caring, it also ensures that the needs of carers to enable them to effectively provide care are ignored.

# Linking Carer and Consumer Evaluations

---

## SUSTAINING THE CARE PARTNERSHIP

It must be remembered that there are two main parties in any caring partnership: the person providing care and support – the carer; and the person needing care and support – the consumer. Each person has unique needs and views which are sometimes complementary and sometimes not. However, in order to ensure the needs of both these groups are met and the care partnership is sustained, the different perspectives and requirements of these groups need to be acknowledged and understood, and ideally consensus reached.

While CNSW agrees that the aim of the MH-CoPES project – to enable consumers to provide input into the evaluation of mental health services – is valuable and entirely relevant, the exclusion of carers from this project has the capacity to seriously undermine the formal recognition of carers and the importance of the care partnership.

If mental health services are to recognise and support the partnership between consumers and carers, any evaluation of their operations and service provision must take account of both the carer and consumer perspective.

This is particularly important for those carers who are under additional pressure to be recognised, such as young carers. Often the ‘hidden’ army of caring within the community, children and young people are generally not recognised as primary carers by the mental health system and yet have the greatest need for information and support.

In Australia, young carers have been identified by services as being as young as 6 years of age, and just under half of young carers are below 18 years of age.

According to the 2003 ABS Survey for Disability, Ageing and Carers (unpublished data), 1 out of 6 carers in Australia (approximately 14.8%) are under 26 years of age. Of these carers, approximately one quarter provide care for someone with a mental illness. However, the Final Report of the Young Carers Research Project (September 2001) notes that services “do not seem to be aware that young carers exist” and that even if young carers are identified, health professionals do not know about their unique needs or how to meet them.

Input from vulnerable carer groups, such as young carers, must be sought at every opportunity to enable services to respond appropriately and effect change as required.

## EVALUATION AIMS

Evaluation in this context should involve assessing the strengths and weaknesses of the service to ensure they are meeting their planned objectives and to improve their effectiveness. It should also enable data to be collected that can be used to:

- identify areas for improvement within the service;
- provide direction for the development of solutions or new initiatives;
- highlight best practice that can be celebrated and shared with other services;
- support the accountability of governments to respond to evaluation findings; and
- facilitate systemic improvement through analysis and public availability of the data.

As part of this process, the views of those utilising the service and interacting with its staff will be a key component. However, self-evaluation may not provide the most meaningful or useful information and could be subject to bias.

Additionally, service evaluation outcomes collected through individual evaluation processes cannot be compared with the evaluation outcomes from other services in order to conduct an independent analysis of each service's effectiveness.

CNSW believes that a consistent approach should be taken to gathering and analysing consumer and carer input regarding the evaluation of mental health services, with an evaluation system developed that can be utilised by an independent body to routinely evaluate the effectiveness of mental health services in NSW in meeting the needs of consumers and carers.

Ideally, analysis and evaluation of the input gathered should be:

- undertaken by external organisations (such as universities or independent researchers) with relevant expertise, and with the associated cost routinely factored in at the initial funding stage; and
- longitudinal, where possible, and attempt to measure the impact of the service provided over time for consumers and carers, which will enable proposed improvements to be evidenced-based.

### **Assessment of caring situation**

Including carers within the evaluation process for mental health services will also provide an opportunity to gather input about carer's capacity and willingness to provide the care required as well as the information, education and support needs they may have in relation to their caring role.

Discharging a consumer into the care of someone who is new to caring, or who is exhausted from providing ongoing care, can have a significant impact on outcomes for both carer and patient. Additionally, carers who are unprepared for the work and stress involved in caring may find it difficult to cope, resulting in withdrawal of their support for the consumer at a critical period or their inability to continue to care due to health and wellbeing problems of their own.

There is often an assumption by mental health professionals that carers are able and willing to take on and continue in a caring role, without any assessment, either formal or informal, of their interest or ability to do so. While many carers enjoy caring for their loved ones and see it as a natural part of a close relationship, carers must be given a choice about caring and their choice must be supported and respected by mental health services.

Continued and regular assessment of a carer's capacity, willingness and needs is also essential. Currently there is no requirement for such assessment and, consequently, no system to gauge the carer's ongoing health and wellbeing. As a carer's emotional, mental and financial needs change over the course of their caring role, it is essential to monitor and assess these needs on a continuing basis to ensure adequate support is provided when and as required.

This is particularly important for those at either end of the carer age spectrum - young carers and ageing carers.

Young carers often experience varying needs and levels of disadvantage as carers as they go through different phases of their own growth and development. Ageing carers will be facing their own health and wellbeing issues as well as concerns around who will take over the care role when they are no longer able to act in this capacity.

In the United Kingdom (UK), the National Service Framework for Mental Health, which sets out the standards the Department of Health expects from its mental health services within the UK, goes some way to addressing this issue. It states that all individuals who provide regular and substantial care for a person should have an assessment of their caring, physical and mental health needs, repeated on at least an annual basis.

Mental health services in NSW need to take a similar approach and ensure that appropriate mechanisms are in place to assess the ability of carers to manage care at home.

## Recommendations

---

In order to support mental health professionals to include carers in the health care team, and ultimately improve outcomes for consumers, it is critical that carers are recognised as important stakeholders in the development of any evaluation system for mental health services.

The following brief recommendations are proposed to provide some recognition of the carer and consumer partnership and ensure that any system of evaluation for mental health services takes account of input from all stakeholders, including carers.

1. Current documentation developed for the MH-CoPES project should be reviewed and modified to ensure the routine inclusion of carers as stakeholders and recognition of the care partnership
2. A component of the project should look at a way to ensure that carers can provide input about mental health services, without detracting from the ability of consumers to provide their own individual input

## References

---

A Welcome Change – submission in response to the release of the Mental Health Draft Exposure Bill – Carers NSW, November 2006

Carer Support Framework – Carers NSW, October 2006

Caring Together – An action plan for carer involvement in Victorian Public Mental Health Services – Victorian Government Department of Human Services, July 2005

Investing in Our Future: Support for Carers in the Budget 2007 – 08 – Carers NSW, October 2006

Respite Reconsidered: A discussion of key issues and future directions for carer respite – Carers NSW, October 2006

Survey of Disability, Ageing and Carers – Australian Bureau of Statistics (2003)

Young Carers Research Project Final Report, September 2001 – Carers Australia