



RESPONSE TO THE MENTAL HEALTH COORDINATING COUNCIL (MHCC) DISCUSSION PAPER

Mapping the Difference We Make : Non Government Organisation Use of Routine Consumer Outcome Evaluation in Providing Mental Health Care in NSW

November 2006

Introduction

ABOUT CARERS NSW

Who we are

Carers NSW (CNSW) is the peak body representing 750,000 carers in this state. Carers are usually family members or friends of any age who provide unpaid care and support to people with a mental illness, disability, chronic condition or who are frail aged.

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 disability, mental illness, chronic condition or who are frail aged. Carers can also 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.

ABOUT THIS RESPONSE PAPER

Carers NSW is pleased to have the opportunity to comment on the MHCC Discussion Paper 'Mapping the Difference We Make', which looks at the importance of a consistent and routine approach to evaluating outcomes for consumers of mental health programs provided by non government organisations (NGO's).

In line with its representative role, and after discussion with Jonine Penrose-Wall, MHCC's consultant researcher, CNSW considered the information and recommendations within the Discussion Paper in terms of the provision of programs for *carers* of consumers with a mental illness or disorder.

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

Accordingly, CNSW asserts any evaluation system for mental health consumer programs needs to recognise :

- the strong link between outcomes for carers of people with a mental illness/disorder and outcomes for consumers themselves;
- the partnership that exists between carers and the person with a mental illness/disorder for whom they care in terms of management of their illness/disorder;
- the important role which carers play in supporting the general health and well-being of the people they care for; and
- the benefits that can be gained from including carers in the evaluation process.

Initiatives for carers

THE ROLE OF CARERS

The vast majority of care for people with a mental illness/disorder occurs in the community, making the role of carer key to the consumer's management of and response to their illness.

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 involves a wide range of tasks and functions.

Carers can provide practical assistance, health care, emotional support, supervision and monitoring. They often also act as advocates on behalf of the person they are supporting.

Practical support may include assisting with showering, toileting, dressing, feeding and communication, or doing laundry, cooking, housework, assisting with mobility in and out of the home and managing financial affairs. Health care includes arranging appointments and liaising with health care professionals, administering medication, preparing special diets, assisting with therapies and treatments, dressing wounds and so on. Emotional support includes encouraging the person, providing companionship and being responsive to their psychological well-being, while supervision and monitoring involve being aware of changes in a person's symptoms or condition and ensuring that they are meeting treatment or medication regimes.

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. Additionally, the carer needs to balance the specific caring role with their other family and work responsibilities as well as their own individual needs.

WHY CARERS NEED SUPPORT

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.

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.

If carers are to continue to provide care and support in the community, it is critical that they are able to access a range of initiatives and programs within an overarching system of support that will extend and consolidate a carer's capacity and ultimately lead to improved outcomes for consumers.

HOW SUPPORTING CARERS BENEFITS CONSUMERS

International evidence suggests that increased investment in carer support not only improves quality of life for carers, it also has a positive impact on those they support. In July 2005, Premier Morris Iemma noted that "better support for families and carers has significant long-term benefits for the whole community, not just those being cared for." (Hansard 23 June 2005, NSW Parliament).

For example, positive outcomes identified for carers provided with respite care (Respite Reconsidered, Carers NSW 2006) include:

- the maintenance of important activities, such as employment
- the maintenance of family and other relationships, including with spouse and friends
- improved general health and well-being, including mental health

In many cases, this support for carers translates into a range of benefits for the care recipient or consumer, such as:

- increased opportunities for social participation
- improved relationship with their carer
- maintenance of the quality of care received

Another form of support for carers is their inclusion within the care team and recognition of their skills and knowledge. One of the most important principles of effective carer support, as identified by Carers NSW over the past 25 years (Carers Support, 2003), is the inclusion of carers at every stage of service planning and delivery.

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 patients and reducing health care costs. For consumers, there is increased compliance with discharge plans and the prevention of readmissions; for mental health professionals, there is valuable information and feedback, which can contribute to effective planning and management.

In terms of initiatives or programs, this could include the provision of training to service providers about the role of a carer and the benefits of including them.

IMPORTANCE OF LINKING CARER AND CONSUMER EVALUATIONS

Support for carers is an investment which prevents the caring relationship from breaking down, prevents carers' health from deteriorating and reduces costs to the community by delaying the institutionalisation of people requiring support.

However, it must be remembered that there are two main parties in any caring relationship: the primary carer and person needing support. Each person has unique needs and views which are sometimes complementary and sometimes not. Carer support initiatives, as well as services for the person requiring care, should work together to support the caring relationship.

In order to assess which support initiatives are most effective for carers and consumers, evidence must be collected through a rigorous evaluation process.

Evaluation in this context should involve assessing the strengths and weaknesses of initiatives or programs 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:

- provide direction for the development of future initiatives;
- enable the redesign of existing programs, where required;
- support the accountability of governments to respond to evaluation findings; and
- facilitate systemic improvement through analysis and public availability of the data.

However, individual evaluation of initiatives undertaken by the organisations that deliver them may not provide the most meaningful or useful information and could be subject to bias. Additionally, program evaluation outcomes collected through individual evaluation processes cannot be compared with other program outcomes in order to conduct an independent analysis of each program's effectiveness and continued relevance.

CNSW believes that a consistent approach should be taken to evaluating initiatives for carers and consumers, with an evaluation system developed that can be utilised by all non-government organisation (NGOs) to evaluate the carer and consumer-focused programs or initiatives they deliver. To support buy-in from the sector, such a system should be developed in consultation and collaboration with the NGOs that provide such services.

Ideally, evaluations should be:

- undertaken by external organisations (such as universities or independent researchers) which have the expertise to conduct them, with the associated cost routinely factored in at the initial funding stage; and
- longitudinal, where possible, and attempt to measure the impact of interventions over time for carers, which will enable the future development of support initiatives for carers to be evidenced-based.

Conclusion

CNSW understands that the *MHCC Discussion Paper : Mapping the Difference We Make* is focused on the need for a system of agreed outcome measurement for NGOs who provide mental health programs. However, any proposed evaluation system must factor in the important partnership between carers and consumers and the strong link between outcomes for carers and outcomes for consumers.

Including carers in the evaluation process for consumer programs will lead to a more holistic approach to the development and delivery of programs and recognition that their main aim is to provide the best possible outcomes for consumers and their families.

RECOMMENDATIONS

The following brief recommendations are proposed to provide some recognition of the carer and consumer partnership and ensure that consideration is given to the way in which the health and well-being of the carer can impact upon the consumer's management of their illness/disorder.

1. Any evaluation system or 'routine consumer health outcome measurement' (RCOM) developed to measure outcomes for consumers of mental health services or programs should also measure outcomes for carers
2. A consistent approach should be taken to evaluating or routinely measuring outcomes for carers and consumers, with a system developed and adopted in consultation with relevant NGOs
3. Such a system should involve the use of external facilities, such as universities, to ensure the evaluation process is rigorous and free from bias and additional core funding should be provided to support this process or a funding component factored into the individual program's budget
4. Information gathered through the evaluation process should be freely available to participating NGOs to support future modification or redesign of programs

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