

Model for Consumer and Carer Involvement in Treatment Planning

Introduction

In 2005, the Department of Health and Aging commissioned Health Outcomes International (HOI) to undertake a study highlighting the benefits of involving consumers and carers in comorbidity treatment planning processes.

The study included the conduct and documentation of a literature review, including national and international information on carer and consumer involvement in mental health, alcohol and drug and comorbidity services.

In addition to the literature review HOI conducted several workshops to engage a range of consumer groups, representative of people with substance use, mental health disorders as well as government and non-government sectors.

As a result of the findings of the study the Consumer and Carer Involvement in Comorbidity Treatment Planning Package (the Package) was developed by HOI at the request of the Australian Government Department of Health and Ageing.

Key Points

- Results from the National Drug Strategy Household Survey 2004 report that almost two in five persons who used an illicit drug in the past month reported high or very high levels of psychological distress.
- The current National Drug Strategy 2004-2009 and the Second National Mental Health Plan both recognise the importance of addressing issues around coexisting mental health and substance use disorders.
- Funding for the Package is provided under the National Comorbidity Initiative.
- \$17.9 million over seven years from 2003-04 to 2009-10 has been allocated for the National Comorbidity Initiative.
- The Initiative builds on the National Comorbidity Project, a joint initiative under the National Drug Strategy and the National Mental Health Strategy, which was initiated by the Government in 2000.
- The first stage of the National Comorbidity Project was a comorbidity workshop. Participants included consumers, carers, policy makers, service providers, clinicians and researchers from the mental health and drug and alcohol sectors and general practitioners.
- One of the recommendations of the report of the outcomes of the workshop was that a national policy be developed outlining the requirements for consumer and carer involvement in service planning and feedback.
- There is a concern among carers and consumers that the current system is not coping with their needs, and in particular services are not respecting the experience and knowledge of carers and consumers.
- The involvement of people with coexisting mental health and substance use disorders and their carers in contributing to the development of care plans is essential to ensure that plans are designed to effectively address the needs of consumers and the role of carers in the context of an interdisciplinary service environment.

Conclusion

The model for consumer and carer involvement in treatment planning is a consolidation of all of the feedback from consumers and carers collected by HOI over the course of the project, using the foundation of learning from the literature review. This model is shown on the following page.

Consumers and carers advocated strongly for their involvement to be a driving force and integral to the design, development and completion of future guidelines. Anything less was considered by many participants to be “tokenistic”. In addition to this systemic involvement, there was almost universal support for the involvement of consumers and carers in treatment planning processes at an agency level and an individual level.

At its most fundamental, the model outlines the processes that need to take place within drug and alcohol and mental health agencies to support consumer and carer involvement in comorbidity treatment planning. The Information Kits for both consumers and carers (described below) must be read in conjunction with this model. These Kits provide the detail that supports the model. They are intended to be used as a guide with organisations tailoring to relevant local information.

Using the Model

The first part of the model (“Agency”) identifies the systemic infrastructure (service delivery principles, training, policies and forms) that agencies require in order to be able to support consumer and carer involvement in treatment planning. In addition, it also notes the need for formal agreements with complementary services (ie those services that are likely to be needed or used by this agency’s consumers). Individual forms and policies that are required are separately identified.

The second part of the model (“Treatment Planning Processes”) describes the stages that are likely to occur (although they may occur contemporaneously) in a single episode of care. This process very much reflects a typical or generic process and obviously needs to be tailored to the individual circumstances of each agency. However, regardless of how they are carried out, it is likely that most agencies would engage in an episode of care with a client that would have much in common with this generic process.

At each stage of the process, there are a range of actions that are required to be taken by the agency in order to facilitate the active participation of both consumers and carers in the treatment planning process. Each of these actions is listed. Some of them require the use of a form and these are clearly identified in the Information Kits (with a description of the contents of the form).

There were also suggestions that consumer and carer representatives should be involved at a structural level in the management of agencies. All of these tiers of involvement have been incorporated in the model and are reflected in the model’s underpinning principles.

UNDERPINNING PRINCIPLES (OF THE MODEL)

To avoid duplication at each level of the model, it is necessary to set out its underpinning principles. These were refined in the course of the workshops and are considered fundamental to the effective implementation of the model.

- At all levels of service delivery (policy making, agency management, case management), consumers and carers must work in partnership with agencies (and government). Consultation is not a substitute for participation and partnership. Whilst consultation may be a component of participation and partnership, alone is not sufficient. Partnership is about:
 - working collaboratively to achieve a common set of objectives,
 - sharing ownership and decision-making and
 - defining and solving problems at both governance and service provision levels.
- Consumers and carers partner with the organisation at a structural level. This means they are integral to the development of organisational policies, processes and resources, the design and delivery of training programs and the management of the organisation.
- Consumers and their carers (where consent is given) participate in every step of the assessment and treatment process, including in assessment.
- Strategies are implemented to cater for the needs of people with low levels of literacy, people with temporary competency issues, people from culturally and linguistically diverse backgrounds, indigenous people, people with physical and intellectual disabilities. (This is particularly important in terms of ability to give informed consent). These strategies should make use of the innovative communication mediums that may employ different types of multi-media.
- The needs of each individual are catered for – their ability to absorb information at any particular time, their interest in being involved, their willingness to participate, their capacity to participate. This should be reviewed periodically (90 days maximum).
- All forms need check boxes, actions to be done and who is to do them and by when, facility for sign off by consumer (and carer, when they are involved) and the service provider at commencement, and then facility for sign off by the responsible person each time action is completed.
- There must be a regular review of all documents (both for currency and progress against identified goals and timelines). These reviews need to involve consumers (and carers where appropriate).
- An appreciation that divulging personal information is a painful process for the person seeking services and this pain is compounded when having to expose fragility over and over again.

POLICY OUTLINES

The model makes reference to a range of policies that agencies should have in place to support good practice consumer and carer involvement in treatment planning. An outline of the contents of each of these policies is provided below. As with all of the contents of this document, this is provided as a guide or starting point only, and each policy must be reviewed by each agency in partnership with consumers and carers.

CULTURAL & LITERACY POLICY

Consumers and carers with special needs will be catered for. These needs include:

- *Low literacy*
- *English as a second language*
- *Hearing Impaired*
- *Sight Impaired*
- *Physical Disability*
- *Intellectual Disability*
- *Particular cultural issues*
- *Gay, lesbian and transgender persons.*

The strategies this agency will use to address these needs include (but are not restricted to):

- *providing interpreter services when required*
- *involving other agencies (religious and cultural groups) to support the needs of culturally diverse people and ensuring that resources are in clear and simple language and,*
- *wherever possible, produced in multiple formats (video, audio, web) to ensure information is in the appropriate formats to meet the needs of consumers and/or carers.*

PROCESS FOR SERVICE RE-ENTRY POLICY

It is inevitable that some consumers who leave a service will need to re-enter that service at some stage. Accordingly, this contingency will be planned for in the discharge plan.

The process for re-entry to this agency will be made as quick, simple and as streamlined as possible. Strategies include:

- *All the previous files/records will be reviewed on re-entry – consumers will not have to tell their story again.*
- *Contact with other agencies involved will be made.*
- *Review of the previous treatment plan to identify what worked and what didn't.*
- *Contact will be made with the nominated carer (subject to consents) to identify the triggers for re-entry.*
- *Wherever possible, the same workers will be allocated to the case.*

CONSUMER AND CARER PARTICIPATION POLICY

The participation of consumers and carers in all that this agency does is integral to a successful outcome for our clients. We recognise that consultation alone is insufficient. Rather, we will partner with consumers and carers to work collaboratively to achieve this agency's objectives, and to ensure that ownership and decision-making are shared. This partnering will include:

- *the development of organisational policies, processes and resources,*
- *the design, delivery and evaluation of training programs (including those for staff) and*
- *the management of the organisation.*

With respect to service delivery (or treatment), we will partner with consumers and (where they consent) their carers to achieve the treatment goals that have been agreed. This means that consumers will participate (when they choose to) in every possible aspect of their assessment and treatment. Carers will be invited to participate as a partner in the treatment process. In particular:

- *In order to maximise their treatment outcomes, consumers will be strongly encouraged to involve their carer in their treatment.*
- *Both the consumer (and their carer if involved and the necessary consents have been given) will be given regular progress updates.*
- *Consumers and their carers will, at all times be listened to and treated with respect. This includes returning calls promptly.*

PRIVACY & CONFIDENTIALITY POLICY

The confidentiality of private information is defined by legislation. At all times this agency will act in accordance with these legal requirements. However, in the spirit of partnership, we will share information with consumers and carers and other involved agencies (subject to the relevant consents) where it will be in the best interests of the consumer to do so.

Disclosure consents will be in writing and will be reviewed periodically to ensure their ongoing relevance and currency. A component of the disclosure consent will be to identify with whom information can be shared in the event of an emergency or crisis.

We recognise that, in some instances, carers will have a genuine need to access information about the treatment and progress of the person they are caring for (and that this disclosure would be in the best interests of the consumer), but that confidentiality legal requirements can be a barrier to this. We will not use this legal requirement as an excuse, but rather work with the consumer to discuss the benefits of having their carer actively involved in their treatment.

In particular, we will encourage the consumer to share information about their treatment and their progress with their carer, particularly where they are dependent on that carer for such things as food, money and accommodation. Information sharing regarding food, money and accommodation may be particularly relevant to consumers who have dependant children. As is required by law, where we receive information from a non-designated carer or family member, we will not provide that person with any information unless the consumer has consented to that disclosure.