

Care in Your Community – Trials

May 2007

Report from Consumer and Carer Workshop

DLA Phillips Fox; Cordyline Consulting; Capital Foresight

Purpose

This paper provides a summary of outcomes from the Consumer and Carer Consultation workshop, 27 April 2007.

The workshop provided carer and consumer representatives and relevant peak bodies with:

- an update/information on the Care in your community integrated area-based trials; and
- an opportunity to advise on future Carer and Consumer engagement in integrated area-based planning.

Background

The Care in your Community framework includes a commitment to involving consumers and carers in planning activities. The workshop addressed the following questions:

- Involvement can occur at different levels, from information exchange to consumers/carers taking active responsibility for some planning tasks. What level of involvement by consumers/carers is optimal?
- Should involvement be limited to active consumers/carers, or should the broader community (who have an interest in health services and may be future but not current consumers) be engaged actively? How could this be done?
- What factors influence the success of engagement in central and statewide processes? How does this compare with local engagement in the planning networks?
- What are the best structures for consumer/carer involvement? How effective are separate consumer/carer advisory committees; or consumer/carer membership of committees that are responsible for the planning; or direct consultation with consumers and carers about specific issues?
- Should engagement be through peak bodies; or with direct consumers of a service; or both?
- How can engagement of specific needs groups (e.g. indigenous communities, CALD communities) be fostered?
- What is needed to support consumer/carer engagement?
- How do we avoid 'tokenism'?

- What outcomes would consumers/carers expect to see that would indicate an effective process? How will we know if the level of consumer/carer engagement has been optimal?

Each of the Trial sites provided information about their consultation model, with the Outer Eastern Trial providing a more comprehensive brief as a case study. The two carer representatives who participate in the Care in your Community project also gave presentations. The workshop discussed formal and informal mechanisms for involvement in central policy discussions and local planning discussions.

Issues

The plenary session discussed a range of issues that fell within the following topics:

Structure: the structure for consultation should reflect the needs of the task or project, but it should be considered and agreed at the commencement of the planning or policy development process. Involvement should be planned across a continuum of activities ranging from individual care planning, local health service planning through to system change. It is recognised to be more difficult to get involvement from people whose contact with the health system is episodic, but local and central networks are available to assist in recruiting both these people and others whose experience is more long-term and intensive.

Process: discussion between clinicians, managers, consumers and carers should be seen as a two-way process, with each participant able to learn from the experience and perspective of the others. In some limited cases (for instance, seeking stakeholder input to a particular policy initiative before it is released for comment), there may be short-term one-way input. It is important to invest in induction, so consumers' and carers' input can be informed and appropriate to the task.

Resources: a proper consultation process should be resourced appropriately, with consumer and carer representatives receiving adequate recompense for their participation. This mechanism indicates their input is valued, while supporting them to participate in an activity which is not central to their own lives. As well, a consultation processes should be given time to develop a relationship of trust and respect between participants.

Feedback: consumers and carers report frustration with a consultation process which takes input from them but does not provide information back to them about the outcomes of the planning or policy deliberation. Where possible, formal feedback should be provided.

Recognition: The value of consumer and carer consultation is recognised when it is valued and appropriately resourced. Consumers and carers provide a unique perspective to any policy or planning deliberation, which should be recognised as being equally valid with any other perspective. Research into the needs and outcomes of consumer and carer involvement is one way to recognise their engagement. It is important to overcome stereotypes about what consumers and carers want from their health services, and to recognise people may feel intimidated about expressing their views.

Some specific suggestions were made, including:

- at least two consumers/carers should participate in each consultation process, to provide back-up, support and a range of views. In some cases, it may be preferable to include more people;
- carer needs may differ from consumer needs and it should not be assumed that one individual can represent the needs of both groups;
- representative groups can assist in recruitment, but need clear guidance about what is the task to be completed, and what are the experience, knowledge, interests and skills of appropriate participants;
- an appropriate level of payment should be offered;
- minimise the risk of consultation overload and burnout by seeking many possible participants.
- don't wait for people with specific needs (e.g. people with disabilities, indigenous people, people from CALD communities) but embark on specific recruiting strategies.

Heather Wellington, DLA Phillips Fox

Alison Hallahan, Capital Foresight

Campbell Miller, Cordyline Consulting

Appendix 1 – List of participants

Name	Organisation
Christine Walker	Chronic Illness Alliance
Sue Hendy	Council of the Ageing Victoria
Sarah Lord	VIVAIDS Incorporated
Sam Biondo	Victorian Association of Alcohol and Drug Agencies(VAADA)
Beth Bailey	Carers of People with a Mental Illness (Carers Network)
Natasha Kukanja	Ethnic Communities Council
Sophy Athan	Consumer and Carer Representative - CiYC Advisory Group
Eleanor Sumner	Consumer and Carer Representative - CiYC Advisory Group
Elizabeth Walpole	Consumer and Carer Representative - CCCAC
Tricia Malowney	Women's Health Association of Victoria / Victorian Women with Disability Network

Name	Organisation
Gill Pierce	Carers Victoria
Suzanne Baxandall	Diabetes Australia Victoria
Trish Waters	Cancer Council Victoria
Tony McBride	Health Issues Centre
Janet Laverick	DHS
Jenny King	DHS
Anne Frost	DHS
Kiera Dingle	DHS
Tracie Martin	DHS - South East
Jonathon Brown	DHS - Outer East
Greg Blakeley	DHS - Gippsland
Heather Wellington	DLA Phillips Fox
Alison Hallahan	Capital Foresight
Campbell Miller	Cordyline Consulting