Community participation—a mouthful at a time

John Lawrence, Executive Director, Kilmany Family Care, Victoria, Elsie Archer, HCRRA Committee Member (WA North), President Derby Shire Council, Dennis Lennox, Queensland Health’s Medical Advisor for Rural Health Services

Chair: Irene Mills, friends of the Alliance

John Lawrence outlined the details of the Kilmany Family Care model of consumer participation. This model is used by the East Gippsland and Wellington Primary Care Partnership and outlined in the “Guide to Consumer and Carer Participation”. He advocated that for organisations to engage in real representation, they should adopt the principles in this model.

Elsie Archer, by way of contrast, Elsie outlined an example of how consumer participation in her area was done poorly. Elsia described how the WA State Government had allocated local government of implementing a change which would dramatically affect local communities. Not happy to take on that responsibility, local government commenced a full round of consumer consultation on the effects and impact of the changes. The end result was the development of a totally different plan to that envisaged by the State Government but one that was constructed to meet all stakeholder requirements.

Dennis Lennox’s presentation was two pronged. He presented the consumer consultation platform of the government in his State. He contrasted this with the actual process of consumer consultation. The reality is that consumer participation is patchy as is the support it receives.

The discussion that followed acknowledged both formal and informal consumer representation. Formal models involved organisations who had a governance policy which actively sought and supported consumer participation and enlisted the services of consumers who are active, attend regular meetings and presented an informed contribution to the topics under discussion. More prevalent and potentially more powerful, simply on the basis of numbers, is the informal consumer network. Informal consumers are those whose advocacy often arose out of a particular adverse event in their life and who “dipped in and then out” of the system.

The forum debated the support needed by formal and informal consumers to take on the tasks of their representation.

Formal representatives needed:

- training
- a gathering of consumer representatives prior to attending a meeting to discuss issues
- transparency of election of representatives
- recognition of the value of consumer leaders.
The challenges they face include:

- lack of funding
- briefing for consumer representatives by the Board
- two-way process for support and education—the board needs it too.
- facilitator for the role
- lack “true” consumers
- timing of meetings to suit all board members
- recognition of the “equal value” of the consumer point of view and the so-called expert point of view
- perception of “not enough say”
- professional consumer achievement
- educate the community
- role of media—is there a marketing solution for the consumer voice?
- critical debate re: participation
- equip focus groups with the formula to their legitimate claim of “who do we invite”.

Informal consumer participation

- No Government or provider perfect

Challenge

- How do we tap the big number of non-active consumers?
- Need to promote the good work that these information networks are making in order that others can replicate.
- Suggestion of better utilising the internet where stories could be documented and acknowledged.
- Need to tap into these informal networks, use the qualitative information and frame it in a legitimate structure so it is not seen as a “whinge”.

Throughout the discussion, examples of informal consumer participation were identified. A Community nurse from Cobden described a successful suicide support group, the only one of its kind from Port Macquarie to Melbourne. Another example was from Queensland where a community nurse described how she spoke at a range of formal and informal meetings such as play groups, P&C Meetings and shed meetings to discuss a proposed change in the community and fed the information back into the system. This speaker emphasised the value of actually meeting people in their own setting.
RECOMMENDATIONS

The following recommendations were put forward.

1. The National Rural Health Conference recommends that through the consumer representatives on the National Rural Health Alliance and other consumer groups and individuals, an infrastructure be developed to grow and strengthen the consumer presence at the 8th National Rural Health Conference, aimed at delivering a consumer representation strategy encompassing formal and informal networks.

2. That Alliance members and governments encourage and assist rural communities to a radical change of stance in health workforce and health service markets from passive to active engagement.

3. That Alliance members and governments commit to build the capacity of rural communities for active engagement in workforce and service markets.