

# DEVELOPING THE CONSUMER NOMINEE PROGRAM

A Report from the Workshop  
held on  
Friday 15 November 2002

Health Issues Centre

*January 2003*

## **ACKNOWLEDGEMENTS**

This report has been compiled by Health Issues Centre from proceedings of the workshop "*Developing the Consumer Nominee Program*". Health Issues Centre would like to thank all the organisations that participated in the workshop.

### **PARTICIPATING ORGANISATIONS:**

*Absolutely Women's Health*

Arthritis Foundation

Bayside Health

Bayside Health Community Advisory Committee

Tumbukka ATSIC Regional Council

Campespe Primary Care Partnership

Carers Association

Centre for Culture Ethnicity & Health

Children's Hospital

Chronic Illness Alliance

North West Area Mental Health Consumer Consultant

Consumers' Health Forum

Council of Self Help Groups

Council on the Ageing Victoria

Dental Health Community Advisory Committee

Department of Human Services

Eastern Health

Inglewood Community Health Service

Inner South Primary Care Partnership

Melbourne Health

Murdoch Children's Research Institute

Northern Health Community Advisory Committee

Peninsula Health

Peter MacCallum Cancer Institute

Peter MacCallum Cancer Institute Community Advisory Committee

Plenty Valley Community Health Centre

Royal Victorian Eye and Ear Hospital

Southern Health Community Advisory Committee

St Vincent's Health

Victorian AIDS Council

Victorian Mental Illness Awareness Council

Western Health

Western Health Community Advisory Committee

Women's Health Victoria

Youth Affairs Council of Victoria

Health Issues Centre would like to thank the people who made presentations to the workshop:

- Lisa Thorpe - Tumbukka ATSIC Regional Council
- Helen Hopkins - Consumer Health Forum
- Mary Draper - Department of Human Services
- Tanja Bahro - Centre for Culture Ethnicity and Health
- Meg Gulbin - *absolutely women's health*
- Wanda Bennetts - North West Area Mental Health Service

We would especially like to thank those presenters who travelled long distances and who took time from their holidays to attend the workshop.

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Finally, the workshop was an effective process for discussing complex issues and for generating recommendations about how the Consumer Nominee Program can be expanded. The workshop's outcomes benefited from the expertise of the facilitator, Maria Dimpoulos.

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## **EXECUTIVE SUMMARY**

**INTRODUCTION:** Health Issues Centre is keen to develop the capacity of the Consumer Nominee Program to respond to the diversity of requests for consumer participation, and to build the capacity of consumers to shape the health system to better meet the needs of the whole population. Through the Consumer Nominee Program, Health Issues Centre aims to ensure that a broad cross-section of consumer views are heard in health policy debates and that consumer perspectives inform the development of the health care system.

**OBJECTIVES OF THE WORKSHOP:** The Consumer Nominee Program workshop was planned to provide an opportunity to develop partnerships – between consumer organisations, health service providers and consumers – that would build consumer and community participation in the health care sector. The workshop aimed to stimulate discussion and debate about the issues and challenges in nominating consumers onto consultative processes and to develop recommendations to guide Health Issues Centre in the development of its Consumer Nominee Program.

**PLANNING THE WORKSHOP:** Health Issues Centre invited consumers and a diverse range of health related organisations to participate in the workshop. The workshop date was set for Friday 15 November, to be facilitated by Maria Dimopoulos (from MyriaD Consultants). The workshop agenda were structured around three themes: *Membership*, *Linkages* and *Support*, and a series of questions were developed around each theme.

**ISSUES FOR DISCUSSION:** A range of speakers gave presentations on policies, strategies and methodologies in consumer and community participation. This was followed by a brainstorming session. Workshop participants then broke up into three groups to discuss and make recommendations around the three themes. A summary of the issues raised in these discussions follows.

**Membership :** The group that discussed membership issues commented on the broad base of membership across different organisations' constituencies. Getting consumers involved in the health care sector needs a commitment to a partnership approach between organisations and consumers. In order to ensure that consumer participation reflects the diversity in the community, health services need to collect good data, to know the community and consult regularly with them, to develop strategies for building inclusive processes and undertake regular evaluation and monitoring. In developing its Consumer Nominee Program, Health Issues Centre needs to strengthen its links with health promotion activities and evaluation.

The policy environment is vital to creating effective systems and processes that facilitate and encourage consumer and community participation. Health service providers may need training and support to connect with their constituency. In these organisations, consumer and community participation needs to be embedded in job descriptions, and health professionals need training to recognise the diversity of

roles of consumer representation. It would also benefit consumers if they received training in their role as either a nominee or a representative, and some guidance with linking back to the community. Health Issues Centre needs to support consumers to operate effectively, especially when there are difficulties associated with advocacy. A key recommendation is that consumers are, at a minimum, reimbursed for costs associated with being a nominee.

**Linkages:** The group that discussed linkages between health services, consumer organisations and Health Issues Centre, commented on the different ways that organisations will interact with the Consumer Nominee Program. Some organisations will be a source of consumers and consumer networks, from their membership base. Health service providers, and in particular large institutions, such as the Metropolitan Health Services, will want to use the Consumer Nominee Program to tap into these networks. Electronic technology provides opportunities for co-ordinating consumer and organisational needs. The Program needs a Communication Strategy to promote it to potential contributors and users. An effective Program will need ongoing resources. Health Issues Centre could link the Consumer Nominee Program into consumer organisations' communication strategies by developing a database of relevant groups/individuals and formalising relationships between organisation and the Centre. The web provides a range of opportunities for developing these relationship; including the possibility of creating a Consumer Nominee site on Health Issues Centre's website that lists Across Our Desk and asking organisations to include links to Health Issues Centre on their web site.

**Support:** In the discussion about the support needs of consumers, this group commented on the importance of resourcing consumer and community participation. A priority is for organisations to have a policy on paying consumers. Health Issues Centre could help organisations and consumers by ensuring that organisations have a clear understanding of why they want consumer involvement, including ground rules about the expectations on consumers. Health Issues Centre could promote the value of having at least two consumers on a group for peer support and suggesting that consumers be asked to identify their training needs and be resourced to undertake this training. Involving consumers in staff training and induction is an important part of creating cultural change in organisations. Health Issues Centre could develop and deliver training that assist consumers to understand their role, to operate within established meeting procedures and to be an effective advocate. It could develop a Support Program that includes a mentoring and opportunities for debriefing, similar to that developed by the Victorian AIDS Council. Health Issues Centre needs a process for gaining feedback from organisations on consumers who have been nominated through its Program. Health Issues Centre should look at ways to better promote the Consumer Nominee Program. This could include market research to identify and analyse the diversity in the population and to provide relevant data to organisations.

**CONCLUSION:** Through the contribution of speakers and group discussion, the workshop identified a range of strategies for tackling the complex issues around ensuring that consumer and community participation is inclusive of the diversity that characterises the population. Greater participation will require cultural change in organisations and this will challenge the way that some health professionals practice. The workshop discussed a wide range of methodologies for working with consumers and communities. The discussion recognised the need to challenge myths and stereotypes about who is interested in participating in these processes and the important contribution that is made by people who have been historically marginalised from these decision-making processes. The workshop provided an opportunity to draw out issues around representation, and made strong recommendations about the importance of valuing consumer's contributions, knowing the community and ensuring that there is comprehensive feedback, monitoring and evaluation processes integrated into consumer and community participation.

The workshop affirmed the need for a consumer nominee program and demonstrated high levels of support and interest amongst health services for working with Health Issues Centre to improve the program.

## **RECOMMENDATIONS:**

1. Health Issues Centre should involve consumers in the development of its Consumer Nominee Program.
2. Health Issues Centre needs to ensure that consumers are reimbursed at a minimum for any expenses that they incur, and should encourage services to pay for consumer participation.
3. Make the concept of the Consumer Nominee Program reciprocal between Health Issues Centre and agencies with volunteers and consumer representatives. This could include developing a consumer nominee "tree" that links collaborating organisations.
4. Health Issues Centre needs to provide information and advice about effective mechanisms for consumer and community participation to organisations. This needs to include building links with health promotion activities. Effective consumer and community participation needs to include comprehensive feedback, monitoring and evaluation processes.
5. Health Issues Centre needs to identify the strategies that will assist organisation to work with diversity in the community. This would include encouraging organisations to collect information about the community, to recognise attitudes and stereotypes that are a barrier to good quality service, and to develop staff capacity to work with people who are often marginalised and stigmatised by the health system.
6. Health Issues Centre should develop a Communication Strategy for promotion of the Consumer Nominee Program to potential contributors and users. This should identify the possibilities for using information technology to promote the Program.
7. Health Issues Centre should dedicate ongoing resources for training and support for consumers. This needs to include strategies for effective leadership, change management in organisations and communicating with the community.
8. Develop clear processes and guidelines for the Consumer Nominee Program, including how organisations can gain access to the database.
9. Develop Memorandums of Understanding between organisations and Health Issues Centre about how organisations will be networked in the Consumer Nominee Program, and who the Consumer Nominee Program Liaison Person is. This could include a requirement that Health Issues Centre's logo and contact details be provided whenever organisations refer to their involvement in the Consumer Nominee Program.
10. Health Issues Centre should develop a Communication Strategy for its Consumer Nominee Program that promotes the database, the libraries and other services and resources that support consumer participation. The Communication Strategy

should identify how organisations communicate with their members, and how the Consumer Nominee Program it will link into these strategies.

11. Health Issues Centre should develop workshops for CAC Resource Officers, and other organisational staff on health promotion, recruitment strategies and how to support consumers.
12. Health Issues Centre should support organisations by publicising information about consumer and community participation methodologies, job descriptions for consumers, reorienting health services to involve consumers, and working with groups that are marginalised.
13. That Health Issues Centre should always ask organisations using the Consumer Nominee Program if they have a policy on payment and reimbursement, and provide organisations with an example of a best practice guideline on paying consumers.
14. That the development of training to support consumer participation needs to involve consumers, and should address the following:
  - A support program that includes mentoring, peer support, and debriefing,
  - Generic training on the role of a consumer nominee, including how to build networks with other consumers and with the community.
15. That Health Issues Centre work with consumers to develop guidelines for consumers and organisations that address:
  - The role of consumer nominees,
  - The responsibilities of organisations using the Consumer Nominee Program to support consumers and to evaluate the process and outcomes from consumer and community participation activities,
  - The benefits of formalising the roles and responsibilities in an agreement between consumers and organisations.
16. That organisations using the Consumer Nominee Program be encouraged to identify the training and support needs of staff and consumers who will be working together on consumer and community participation projects, and how these projects will be evaluated.
17. That organisations be provided with advice and training about how to effectively involve consumers, and the benefits of having more than one consumer involved in consumer and community participation activities. This will particularly apply to projects working with people from marginalised or stigmatised groups in the community.
18. That Health Issues Centre needs to work with DHS, health services undertaking consumer and community participation and other key stakeholders to ensure that there are ongoing resources for training and support for consumers.

## **INTRODUCTION**

In the past two decades the Australian health industry has experienced a significant shift in community expectations about how decisions should be made about health. People are less likely to expect medical practitioners to be infallible, and more likely to want to understand their diagnosis and to discuss treatment options with their doctor. This trend towards greater participation in medical decision-making is part of a larger movement that acknowledges that consumers have a stake in the development and delivery of health care. More and more, consumers are being called on to contribute to the planning, development, implementation and evaluation of health care.

Health Issues Centre is a non-government organisation that undertakes research into consumer perspectives on health, with a particular focus on consumers who are disadvantaged by current arrangements.

Health Issues Centre argues that consumer interests cover the following spectrum of people in the community:

- As patients interested in the quality of care, effectiveness of treatment and the way that services are delivered,
- As families and carers and as members of self help groups and community networks,
- As citizens concerned about social values and priorities in health policy, planning and delivery of care.

Consumer and community participation is a way of broadening the perspective of health practitioners and policy makers about options for improving the health system. Providing formal processes for consumer participation satisfies the democratic right of people to be involved in decisions about their health care, including individual care, models of service delivery, the governance of our health institutions and government funding and policy decisions. Greater participation from the community in our health care system has the potential to help practitioners and administrators to have a better understanding of the diverse circumstances of consumers, and to build a health system that meets the needs of the community.

Health Issues Centre is keen to develop a Consumer Nominee Program that is responsive to the diversity of requests for consumer participation, and that builds the capacity of consumers to shape the health system to better meet the needs of the whole population. In particular, services need to hear more about the experiences of people whose needs are not met by current models of care. Consumers from marginalised groups face a particular set of difficulties, such as language and cultural difficulties, stigma or discrimination. These difficulties discourage participation from these groups in the design and delivery of health care, which then impacts on access to services and uptake of medical advice. As the World Health Organisation suggests, health services that are sensitive to the needs

of consumers will deliver better health care, as well as a more efficient use of public funds<sup>1</sup> .

Through the Consumer Nominee Program, Health issues Centre aims to ensure that a broad cross-section of consumer views are heard in health policy debates and that consumer perspectives inform the development of the health care system.

## **BACKGROUND**

Health Issues Centre's Consumer Nominee Program emerged out of requests from health related agencies wanting to involve consumers in the research, planning, development, implementation and evaluation of their services. As an organisation with extensive networks into the community sector and consumer groups and organisations, Health Issues Centre is often approached by government departments, hospitals, research organisations and public interest agencies for assistance with identifying consumers interested in participating in consultative processes such as:

- Interviews as part of one-off research,
- Focus groups for evaluating service delivery models,
- Reference groups for reviewing health services or government policies,
- Formal advisory structures like the Community Advisory Committees to hospital Boards.

The Consumer Nominee Program was formally established following the decision to set up a database of people interested in becoming consumer nominees. In 2002, the database has a membership of around 40 organisations, 100 members (mostly individuals) and 100 subscribers to the *Health Issues* journal. Health Issues Centre distributed an information and networking email, giving details about committees seeking consumer representatives. The email went out to members of Health Issues Centre and subscribers to the *Health Issues* Journal. This email became "*Across Our Desk*"; a regular bulletin of information about upcoming conferences, seminars, major policy developments, strategies and opportunities for consumers to participate in committees and comment on developments in the health sector. The Bulletin was a means of electronically linking these requests for consumer representation, allowing consumers to respond directly to one-off requests such as agencies seeking consumer comment on draft government or health service strategies.

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<sup>1</sup> National Health Strategy ( 1993) Healthy Participation Background Paper No12, Prepared for the Department of Health, Housing and Community Services

## AIM OF THE WORKSHOP

In response to increasing requests, Health Issues Centre aims to develop the capacity of the Consumer Nominee Program to match interested consumers with organisations. Health Issues Centre is keen to ensure that there is appropriate and effective representation of consumer concerns and priorities in decision-making processes undertaken by health services. The Centre is also keen to develop a greater understanding of how to resource and support consumers involved in these processes. The workshop was planned to provide an opportunity to develop partnerships – between consumer organisations, health service providers and consumers – that would build consumer and community participation in the health care sector. The Program for the day was organised to:

1. Provide people with information and new and challenging ideas about consumer and community participation,
2. Stimulate discussion and debate about the issues and challenges in nominating consumers onto consultative processes, and to
3. Develop recommendations to guide Health Issues Centre in the development of its Consumer Nominee Program

The Centre approached a wide range of health related organisations to participate. These organisations were sent background information about the Consumer Nominee Program with an explanation of the aims of the workshop, which was held in November 2002 and professionally facilitated<sup>2</sup>. The workshop agenda were structured around three themes: *Membership*, *Linkages* and *Support*, and a series of questions were developed around each theme. These questions would form the basis of the day's discussion<sup>3</sup>.

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<sup>2</sup> See Appendix 1 for a copy of the *Invitation* and Appendix 5 for a list of *Participating Organisations*

<sup>3</sup> See Appendix 3 for a copy of the *Program*

## **PRESENTATIONS**

### **Lisa Thorpe - Tumbukka ATSIC Regional Council**

Lisa Thorpe, from the Tumbukka ATSIC Regional Council, opened the day's proceedings with a traditional welcome, and an overview of the health issues facing Koori and other Aboriginal people in Victoria<sup>4</sup>. Aboriginal people's health and wellbeing continues to be affected by the history of dispossession and the trauma of attempted genocide. Aboriginal understandings of health and wellbeing underscore the importance of holistic health; an individual's health needs to be understood in the context of the health and wellbeing of their family and their community.

Lisa Thorpe suggested that getting greater consumer and community participation in mainstream services from the Aboriginal community begins with identifying the Aboriginal health network and building relationships with local Aboriginal organisations in the community. Developing trust and cooperation in these relationships takes time and commitment, as well as an understanding of competing priorities in the Aboriginal community. Mainstream health services need to support Aboriginal models of service delivery, which operate with the support and involvement of the community. Most of these services are inadequately resourced and struggle to secure recurrent funding, making it difficult to undertake long term strategic planning and to develop partnerships with mainstream health services to better meet the needs of the community.

### **Meredith Carter - Executive Director, Health Issues Centre**

Meredith Carter spoke about progress over the last decade in gaining recognition from the health sector about the benefits of consumer and community participation. For example, Victoria now has Community Advisory Committees advising the Boards of Metropolitan Health Services, and each Primary Care Partnership has a formal structure to ensure active consumer, carer and community involvement.

Health Issues Centre's Consumer Nominee Program developed out of the networks and links that existed between organisations committed to the consumer movement. Since initiating the Program, Health Issues Centre has a greater appreciation of the challenges of recruitment and the importance of education and training to support consumers. The workshop provided an important opportunity to discuss how Health Issues Centre can support greater consumer involvement within organisations, and how to enhance networking. In particular, it offers the opportunity for consumers, community and health organisations to link together, to develop a consumer "tree" amongst collaborating organisations. Through building the capacity of consumers and organisations, we have greater potential to deliver

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<sup>4</sup> Lisa Thorpe's *Presentation* is included at Appendix 6 in the electronic version of this report

improvements in people's health, including addressing the issues of racism and disadvantage that Lisa Thorpe discussed.

### **Maria Dimopoulos – Facilitator**

Maria Dimopoulos reminded participants that the workshop was an opportunity to think about:

- Who is a consumer and how do we develop greater insight into the impact of diversity in the community on that definition?
- What does participation mean? What are the activities that build engagement, dialogue, and the active listening that is needed to break down the barriers between the users and the managers of health services?

### **General Comments**

In the general discussion following the presentations, people commented on the importance of being able to access the research and findings that support consumer and community participation, and of developing ways of collecting anecdotal reports about what different organisations are doing<sup>6</sup>. A simple booklet, or package of information, about the different ways of doing consumer and community participation, was identified as likely to be a helpful resource. There was also some concern that the Department of Human Service's policy on supporting consumer and community participation doesn't always feed down into the service level. This discussion raised important issues about how to:

- Change the culture of organisations?
- Develop leadership amongst consumers and staff?
- Ensure that consumer and community participation is inclusive?
- Challenge any hostility and resistance to consumer and community participation amongst service providers and professionals?
- Better understand the impact of defensive practice within the health system?
- Raise awareness of how health services stigmatise and marginalise certain groups within the community?

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<sup>6</sup> The *National Resource Centre for Consumer Participation in Health* has a large collection of resources in its library and on its website: [www.participateinhealth.org.au](http://www.participateinhealth.org.au), or Tel: 1800 625 619

## Helen Hopkins - Executive Director Consumers' Health Forum

Helen Hopkins gave a presentation titled "*Achieving Good Practice in Consumer Representation*"<sup>7</sup>. The Consumers' Health Forum's Consumer Representation Program follows a series of steps to nominate consumers on to committees. Consumers' Health Forum (CHF) will discuss the request with the organisation seeking a nominee and clarify practical details such as the meeting location and time, sitting fees and reimbursement of incidental costs, as well as explain CHF's process for recruitment. These requests are then included in CHF's monthly newsletter. Interested consumers contact CHF and submit a nomination form that includes an endorsement from a relevant organisation or consumer body, to ensure that the representative is affiliated to a network of consumers for consultation and accountability processes. These '*Expressions Of Interest*' go to a Consumer Representatives Subcommittee, made up of people from the Board of CHF, who assess the applications against selection criteria. Once they are selected, consumers receive a package of information. This includes an agreement between CHF and the consumer about the support that CHF will provide to the consumer and the obligations of the consumer as a representative on a committee. Consumers also receive a copy of the CHF publication "*Guidelines for Consumer Representatives*"<sup>8</sup>, and a form to provide feedback or comments after meetings to CHF. These reports form the basis of CHF's support to consumers, and can include, for example, requests for information about confidentiality, or to discuss issues that may require CHF to advocate on behalf of the consumer (such as late provision of meeting documents or reimbursement of incidentals). CHF is also keen to develop greater networking opportunities for representatives, through mentoring, website discussion forums, or linking consumers with shared interests.

The Review of the Consumer Representation Program found that there had been a huge growth in the requests for consumers, and that this has not been matched by a similar growth in CHF resources. In addition to recommending that CHF be funded to built its capacity to support the Program, the Review found a need for:

- Training for consumer representatives,
- Strengthened accountability procedures,
- Consistent policy advice to the Department of Health and Aging around issues such as payment of sitting fees and the special needs of consumers, and
- Greater capacity to respond to urgent requests form committees.

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<sup>7</sup> Helen Hopkin's *Presentation* is included in Appendix 7 in the electronic version of this report

<sup>8</sup> Consumers' Health Forum (1999) Guidelines for Consumer Representatives 4<sup>th</sup> edition Lyons ACT

## **Mary Draper - Manager; Effectiveness Unit, DHS**

After morning tea, Mary Draper spoke about the policy environment within DHS. It is important to note that there is bi-partisan support for consumer and community participation in health care in Victoria. Consumer and community participation is also embedded in the quality service agenda of DHS.

This is symptomatic of the underlying cultural shift towards greater support for consumer involvement, especially in the hospital sector. The commitment, however, is not necessarily matched by knowledge of how to go about it. Hospitals are large and heterogeneous organisations and, while there are pockets of interesting activity, the challenge is to capitalise on projects and consolidate these developments in the core business of services.

Health services are increasingly interested in building organisational capacity around consumer participation. The Austin and Repatriation Medical Centre used the Consumer Nominee Program to recruit consumers for the Clinical Support Systems Project. Despite their being no obvious group to recruit from, Health Issues Centre was able to convene and facilitate consumer focus groups. Participants on these groups were then recruited to ongoing reference groups that improved the quality of services in the Austin project. Participation in the project also built the capacity of the consumers involved, who are now keen to use these skills in other areas<sup>9</sup>.

Consumers are often motivated to participate in these kinds of projects in order to improve the quality of health care and to influence decisions about their care. Consumers need to be involved across the spectrum of decision-making, from personal care to governance level. Becoming involved in committees and projects provides an opportunity to build these personal experiences into a collective consumer consciousness. It is important that the two ends of this continuum, personal experience and formal consultative processes, support and inform each other. Dialogue between consumers and providers needs to be interactive, not passive, and the greatest achievements often follow from the most feisty debates. This level of engagement requires that consumers have specific skills in order to be effective in those settings, and the Consumer Nominee Program needs to support this.

## **Tanja Bahro - Centre for Culture Ethnicity and Health**

Tanja Bahro talked about the findings that are emerging from the Acute Care Diversity Project that is being undertaken by the Centre for Culture Ethnicity and Health. All Victorian hospitals need to be more accessible to the diverse cultural and ethnic groups within the community. People from these population groups may be isolated and marginalised but together they make up at least a quarter of the

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<sup>9</sup> For more information about this project, go to <http://home.vicnet.net.au/~hissues/projects.htm>.

population in Victoria. While data collection about access and usage rates is inadequate for an accurate assessment of need, provision of culturally and linguistically appropriate services has the potential to improve health outcomes and to significantly decrease hospital costs. Assistance with communication (training for staff, provision of interpreters) can achieve reduced length of stay, better compliance with treatment advice and reduced need for exploratory tests.

Hospitals need to respond to cultural and language diversity by ensuring that their service is accessible to all the population. This would include evaluating the levels of access for the local community, improving data collection, and resourcing and training staff to recognise and respond appropriately to the needs of the community that they serve.

While consumer participation is a growing area in health, the levels of participation from culturally and linguistically diverse communities in planning and service development are inadequate. Membership of committees like the Community Advisory Committees (CACs) requires that people have a place to live, time to spare, adequate income, proficiency in English, and are familiar with and assertive in Anglo-Australians systems of service and decision-making. Greater diversity of participation could be encouraged through:

- The identification of positions for representatives from specific groups,
- Payment of sitting fees
- The provision of training, and
- The establishment of portfolios within Community Advisory Committees.

CACs also need to develop real structures for gaining feedback from the community, informing the community of its work and reporting on the implementation of its recommendations<sup>10</sup>.

### **Meg Gulbin - *absolutely women's health***

Meg Gulbin spoke about the health promotion program, *absolutely women's health*, part of the Women's Health Program at the Royal Women's Hospital. The program is for all women, with a particular focus on women who are marginalised by the health system. A range of health promotion and community development strategies are used to work with young women, lesbians, Aboriginal women, women on low incomes and women from culturally and linguistically diverse communities. The yearly evaluation, for example, identified the need for sexual and reproductive health information targeted to young women. The program has used consumer focus groups to test the quality of literature for patients, to identify the training needs of service providers and issues in lesbian women's health. As a result of these consultations, the program has

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<sup>10</sup> Tanja Bahro's *Presentation "making waves"* is included in Appendix 8 of the electronic versions of this report

- Organised a good practice forum about young women and depression for service providers,
- Organised a forum on lesbian women's access to IVF and fertility treatments,
- Developed parenting information booklets to meet the needs of single mothers and lesbian families, and
- Developed printed and web information on particular health issues such as Hormone Replacement Therapy and Polycystic Ovarian Syndrome.

*absolutely women's health* organises events, such as women's health days, to increase women's knowledge about, and familiarity with, the services available at the Royal Women's Hospital. While it has been less successful in reaching the target audience in rural areas — due to limited resources and the belief that good quality information comes from community based practitioners with an understanding of the local area — the program is well regarded for addressing contemporary and contentious health issues<sup>11</sup>.

### **Wanda Bennetts – Consumer Consultant**

Wanda Bennetts from North West Area Mental Health Services spoke about "*Making It Happen, From Policy to Picture Books*". The mental health system has historically constructed patients as passive and irrational, and therefore unable to provide reliable information about the quality of care. Many consumers have experienced a mental health system that can be cruel and humiliating and that has robbed people of their dignity. Working as a consumer consultant has presented opportunities for consumers to tell their version of the truth about mental health services. This version, like the perspective of the wolf in the tale of the three little pigs, can provide a different angle on a familiar story. The perspective of consumers needs to be recognised and integrated into the mental health care system.

Being a consumer consultant has involved a broad range of activities including, but not limited to:

- spending time talking to people in in-patient units,
- feeding back their comments to staff and management,
- being involved in staff selection processes,
- providing consumer input into the training of clinicians.

In thinking about how to challenge the power structures in mental health, Sally Thorne's article "*Constructive non-Compliance in Chronic Illness*<sup>12</sup>" has been useful for thinking differently about compliance and the relationships between consumers

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<sup>11</sup> For more information, contact *absolutely women's health* between Monday and Thursday, at 132 Grattan St, Carlton, Victoria, Tel: Ph: 03 9344 2199, <http://wellwomen.rwh.org.au>. or by emailing [absolutely.womens@rwh.org.au](mailto:absolutely.womens@rwh.org.au).

<sup>12</sup> Sally E Thorne " *Constructive noncompliance in chronic illness*" *Holistic Nurs Pract* 1990; 5(1): 62-69

and their clinicians. Consumers will often make decisions about their own care that differ from the treatment regime prescribed by their practitioner. These decisions reflect a greater knowledge of personal circumstances and health and wellbeing, including personal values about quality of life. Unfortunately, consumer's decisions to modify and tailor their treatment can often earn a rebuke from clinicians, who sometimes pathologise consumers for their "non-compliance". Instead of trivialising consumer knowledge, values and experience, health services need to recognise and value consumers' specific understanding of the social context of their health care.

Consumer consultants efforts to breakdown health professional's resistance to consumer participation can take a personal toll, especially when the process becomes adversarial and conflict is personalised. The work can also be extremely distressing, especially when decisions are made for the ease of the system not for the benefit of consumers. It is important that consumers working in these circumstances have a range of strategies for providing support, trusted feedback and debriefing<sup>13</sup>.

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<sup>13</sup> Wanda Bennett's *Presentation "Making It Happen"* is included in Appendix 9 of the electronic copies of this report

## **BRAINSTORMING THE ISSUES**

Following the presentations from speakers, a brainstorming exercise came up with the following comments across the three themes of membership, linkages and support.

### **MEMBERSHIP**

- Must have consumer involvement in developing the Consumer Nominee Program.
- Can consumers really be representative? Can we represent every consumer?
- It may help consumer nominees if they have regular opportunities to meet, to develop networks and share ideas about effective strategies.
- CACs could develop portfolios to address the needs of, for example, specific interest groups, young people, refugees and new arrivals.
- The myths and stereotypes about consumers, for example about young people not having an interest or an opinion, need to be recognised and challenged.
- Consumer participation needs to include strategies for engaging young people, see YacVic Handbook.
- Health Issues Centre's Consumer Nominee Program needs a Communication Strategy to promote what it does.

### **Linkages**

- The assumptions about the homogeneity of consumers need to be challenged.
- Organisations need more information about consultation methodologies, and strategies for improving accountability and communication.
- Good practice models for strengthening relationships need to be identified.
- The many levels and forms of consumer and community participation need to be documented.
- Problems need to be addressed at the roots, not just the symptoms.

### **Support**

- Develop job descriptions for consumer representatives, including feedback mechanisms.
- How are networks sustained?
- Can consumers support staff around consumer and community participation?
- Ensure that decisions, such as meeting times, meet the needs of consumers, and be sensitive to arrangements that make it difficult for people to participate.
- Consumers need resources and access to the literature and case studies.
- Language is an important factor in the power relations between consumers and service providers.

- Some health professionals need to be challenged about their assumptions about consumers. Good consumer and community participation causes change, and some service providers will feel inconvenienced, defensive or threatened by this change.
- Consumer and community participation needs to be normalised, the stages of change identified, and consumers need to be supported to manage the challenges that are involved in this change.
- It is harder to do consumer and community participation in large organisations, where the system swallows innovation.

## **GROUP WORK**

After lunch, and after watching the video "*The Solution Oriented Mind Set*", participants broke up into three groups to discuss and make recommendations around the three themes identified in the previous section. A summary of the issues raised in these discussions is detailed, along with the recommendations made by each group.

### **Membership**

In response to the questions about membership, the group commented on the broad base of organisations' constituencies, in terms of geographic catchments, particular socio-economic groups, cultural and linguistic diversity, people with a disability, who are isolated, etc. Getting consumers involved in the health care sector needs a commitment to a genuine partnership approach between organisation and consumers. The policy environment within organisations is vital to creating an environment, a structure and effective processes that facilitate and encourage consumer and community participation. Organisations may need training and support to connect with their constituency. In order to ensure that consumer participation reflects the diversity in the community, organisation need to:

- collect good data,
- know the people who use the service,
- know the community and consult regularly with them, and
- develop strategies for building inclusive processes.

Evaluation and monitoring activities needs to identify diversity in the community and that ensure that emerging issues are integrated into a planning cycle. In developing its program, Health Issues Centre needs to consider building links with health promotion activities and evaluation. The *Ottawa Charter* provides a framework for informing Health Issues Centre about how it can increase the membership of its

Consumer Nominee Program. Electronic technology provides opportunities for coordinating consumer and organisational needs.

In organisations, consumer and community participation needs to be embedded in job descriptions, and staff need training to recognise the diversity of roles of consumer representation. This may entail a debate about the meaning of a consumer. It would also benefit consumers if they received training in their role as a nominee or a representative, and some guidance with linking back to the community.

Health Issues Centre's Consumer Nominee Program needs to support individuals and group to operate effectively, especially when there are difficulties associated with advocacy. A key recommendation is that consumers are, at a minimum, reimbursed for costs associated with being a nominee.

The Program needs a Communication Strategy to promote the program to potential contributors and users, to make connections with other service providers and to ensure reciprocity, rather than competition, in the relationship between Health Issues Centre and organisations who have their own membership base of consumers. An effective program will need ongoing resources.

These comments were condensed down into the following recommendations.

## **Recommendations**

1. Health Issues Centre should involve consumers in the development of its Consumer Nominee Program.
2. Health Issues Centre needs to ensure that consumers are reimbursed at a minimum for any expenses that they incur, and should encourage services to pay for consumer participation.
3. Make the concept of the Consumer Nominee Program reciprocal between Health Issues Centre and agencies with volunteers and consumer representatives. This could include developing a consumer nominee "tree" that links collaborating organisations.
4. Health Issues Centre needs to provide information and advice about effective mechanisms for consumer and community participation to organisations. This needs to include building links with health promotion activities. Effective consumer and community participation needs to include comprehensive feedback, monitoring and evaluation processes.
5. Health Issues Centre needs to identify the strategies that will assist organisation to work with diversity in the community. This would include encouraging organisations to collect information about the community, to recognise attitudes and stereotypes that are a barrier to good quality service, and to develop staff

capacity to work with people who are often marginalised and stigmatised by the health system.

6. Health Issues Centre should develop a Communication Strategy for promotion of the Consumer Nominee Program to potential contributors and users. This should identify the possibilities for using information technology to promote the Program.
7. Health Issues Centre should dedicate ongoing resources for training and support for consumers. This needs to include strategies for effective leadership, change management in organisations and communicating with the community.

## **Linkages**

In response to questions about how Health Issues Centre could strengthen networking between organisations and consumers, the group made a number of suggestions:

- Health issues Centre should advise organisations of who to contact for information about the Consumer Nominee Program.
- Health Issues Centre should consider sharing its database with participating organisations, and marketing *Across Our Desk* and resources such as the National Resource Centre for Consumer Participation in Health's on-line library to interested organisations.
- Workshops on health promotion, recruitment and support for consumers should be conducted to assist organisations to work with consumers.

Organisations communicate with their membership through open days, newsletters, web sites, email, mail outs, media releases, local papers/media, Annual Reports, Quality of Care Reports, phone enquiry's etc. Health Issues Centre could link the Consumer Nominee Program into these communication strategies by developing a database of relevant groups/individuals and formalising relationships between organisation and Health Issues Centre with an Memorandum of Understanding. The Centre could make its logo and contact details available for use by organisations on their publications. It would help organisations if Health Issues Centre promoted an identified liaison position. The world wide web provides a range of opportunities for developing these relationships including creating a Consumer Nominee Program site on Health Issues Centre's website that lists *Across Our Desk* and asking organisations to provide links from their web sites to Health Issues Centre.

## **Recommendations**

8. Develop clear processes and guidelines for the Consumer Nominee Program, including how organisations can gain access to the database.

9. Develop Memorandums of Understanding between organisations and Health Issues Centre about how organisations will be networked in the Consumer Nominee Program, and who the Consumer Nominee Program Liaison Person is. This could include a requirement that Health Issues Centre's logo and contact details be provided whenever organisations refer to their involvement in the Consumer Nominee Program.
10. Health Issues Centre should develop a Communication Strategy for its Consumer Nominee Program that promotes the database, the libraries and other services and resources that support consumer participation. The Communication Strategy should identify how organisations communicate with their members, and how the Consumer Nominee Program it will link into these strategies.
11. Health Issues Centre should develop workshops for CAC Resource Officers, and other organisational staff on health promotion, recruitment strategies and how to support consumers.
12. Health Issues Centre should support organisations by publicising information about consumer and community participation methodologies, job descriptions for consumers, reorienting health services to involve consumers, and working with groups that are marginalised.

## **Support**

In the discussion about the support needs of consumers, this group commented on the importance of resourcing consumer and community participation. Organisations need to have a policy on paying consumers. This is a priority. This policy needs to clearly define whether consumers will be paid sitting fees and reimbursed for costs, what members will be paid, what the bench marks for payment are etc.

Health Issues Centre needs to ensure that organisations have a clear understanding of why they want consumer involvement, including ground rules about the expectations on consumers. A formal "contract" between consumers and organisations, including guidelines, would help in this process. It was suggested that consumers be asked to identify their training needs and be resourced to undertake this training, as part of the "contract".

Health Issues Centre could promote the value of having at least two consumers on a group for peer support. Involving consumers in staff training and induction is an important element in creating cultural change in organisations. Training for staff needs to include understanding the terminology in consumer and community participation, such as "consumer nominee", and developing clear role descriptions and information about processes for meaningful involvement of consumers at all levels.

Health Issues Centre could develop a training program that assist consumers to understand how to take up their role, that increased their confidence to speak up,

to raises issues effectively, to operate within established meeting procedures and to be an effective advocate. It could develop a Mentoring Program, similar to that developed by the Victorian AIDS Council, which includes opportunities for debriefing.

Health Issues Centre needs a process for gaining feedback from organisations on consumers who have been nominated through its Program. Health Issues Centre should look at ways to better promote the Consumer Nominee Program. This could include market research to identify and analyse the diversity in the population and to provide relevant data to organisations.

## **Recommendations**

13. That Health Issues Centre should always ask organisations using the Consumer Nominee Program if they have a policy on payment and reimbursement, and provide organisations with an example of a best practice guideline on paying consumers.

14. That the development of training to support consumer participation needs to involve consumers, and should address the following:

- A support program that includes mentoring, peer support, and debriefing
- Generic training on the role of a consumer nominee, including how to build networks with other consumers and with the community.

15. That Health Issues Centre work with consumers to develop guidelines for consumers and organisations that address:

- The role of consumer nominees,
- The responsibilities of organisations using the Consumer Nominee Program to support consumers and to evaluate the process and outcomes from consumer and community participation activities.
- The benefits of formalising the roles and responsibilities in an agreement between consumers and organisations.

16. That organisations using the Consumer Nominee Program be encouraged to identify the training and support needs of staff and consumers who will be working together on consumer and community participation projects, and how these projects will be evaluated.

17. That organisations be provided with advice and training about how to effectively involve consumers, and the benefits of having more than one consumer involved in consumer and community participation activities. This will particularly apply to projects working with people from marginalised or stigmatised groups in the community.

18. That Health Issues Centre needs to work with DHS, health services undertaking consumer and community participation and other key stakeholders to ensure that there are ongoing resources for training and support for consumers.

## **CONCLUSION:**

The workshop was a valuable opportunity for consumers, representatives from health services and staff from Health Issues Centre to discuss how to increase consumer and community participation in the health sector. It affirmed the need for a Consumer Nominee Program and demonstrated high levels of support and interest amongst consumers and health services for working with Health Issues Centre to develop the Program. Through the contribution of speakers and group discussion, the workshop identified a range of strategies for tackling the complex issues around ensuring that consumer and community participation is inclusive of the diverse groups in the population.

Greater participation will require cultural change in organisations and this will challenge the way that some health professionals practice. The workshop discussed a wide range of methodologies for working with consumers and communities. The discussion recognised the need to challenge myths and stereotypes about who is interested in participating in these processes and the important contribution that is made by people who have been historically marginalised from these decision-making processes.

It also provided an opportunity to draw out issues around representation. Strong recommendations were made addressing the importance of knowing the community and ensuring that there is comprehensive feedback, monitoring and evaluation integrated into consumer and community participation processes. The recommendations focused on the need for Health Issues Centre to develop a Communication Strategy to strengthen its relationships with organisations. The workshop also recommended a comprehensive Training And Support Program for consumers. Finally, it identified the need to build the capacity of health services by providing better information, advice and direction to organisations about the evidence supporting effective consumer and community participation.

## **WORKSHOP EVALUATION**

An evaluation form was given to participants with their program. The evaluation had a return rate of 17 from a possible 32 participants (53%).

### **BENEFITS OF THE WORKSHOP:**

The majority of responses reported that the workshop had been useful, with comments on:

- The quality of the speakers and the facilitation
- A good framework for identifying the key issues and suggested solutions,
- A good opportunity to share experiences, ideas and formulate strategies for improved consumer and community participation
- Range of good ideas discussed, opportunity to network
- Useful for directing policy in organisations, considering the complexity of issues around consumer and community participation and generating new ideas

In particular, participants appreciated the opportunity:

- To get useful ideas from speakers, such as the idea of portfolios, and information about what was being achieved in other areas
- To think creatively about, for example, how to support consumers, and to discuss issues, such as the difference between nominees and representatives,
- To reflect on what is known, to identify priorities, to develop practical strategies

People welcomed the opportunity to have involvement and make recommendations about the development of Health Issues Centre's CNP. However, while some people felt that their input was heard, others thought that the possibility was not clearly explained during the workshop proceedings or that it was very limited. The evaluation included comments that Health Issues Centre had received clear recommendations about the priority placed on training and support for consumer and community participation, and on focusing CNP activity at the "grass roots".

People found the workshop a good opportunity for networking, and that this was a valuable part of the day that needed more time.

### **AREAS FOR IMPROVEMENT**

Other helpful feedback from the evaluation included the following comments from some participants:

- The need to develop stronger conceptual linkages with health promotion
- Participants needed more information about the CNP Program, the relationship between the workshop and the development of the CNP, and the links between the purpose of the workshop and the speakers

- Consumer and community participation needs to be framed within a broader processes than just committees such as the CACs
- The day was too long and could have finished earlier

## APPENDIX 1- INVITATION TO PARTICIPATE IN THE WORKSHOP

This email, with some variation, was sent to organisations asking them if they would be interested in participating in the workshop.

I am writing to ask if (*organisations name*) is interested in participating in a Workshop to look at Health Issues Centre's Consumer Nominee Program? Health Issues Centre is often approached to provide consumer representatives to various types of consultative processes. These include:

- interviews as part of research,
- participation in focus groups,
- reference groups for reviewing health services or policies,
- formal advisory structures like the Community Advisory Committees to Metropolitan Health Services.

We get these requests from government departments, hospitals, research organisations and public interest agencies. Health Issues Centre's Consumer Nominee Program facilitates this involvement by maintaining a database of people interested in becoming consumers on committees etc. As part of their membership on this database, people get sent a copy of "*Across Our Desk*", a regular email bulletin that features new health policy developments, conferences etc and includes information about committees that are looking for consumers.

I would like to get a group of representatives from the community health sector (I am approaching people at Women's Health Victoria, Centre for Culture Ethnicity and Health, VIC AIDS, the Inner South Primary Care Partnership, Ethnic Communities Council of Victoria ) together with consumer organisations, - Consumer's Health Forum, COTA, Victorian Mental Health Illness Awareness Council, YACVIC, Chronic Illness Alliance, and some DHS representatives (from the Acute Section) to form a Reference Group, to look at the Consumer Nominee Program, and provide us with some advice on;

1. Improving the recruitment process,
2. how to link consumers into the various committees involved in MHSs (the project will have an acute focus in the first stage) and
3. how to better support members and consumer advisory processes and committees.

At this stage, I am not sure what sort of time commitment this Reference Group might involve. I would like to organise the first meeting as a workshop to brainstorm, and based on the suggestions and options that come out of that, develop the project from there. Can you ring me to discuss if (*organisations name*) is interested in being involved?

Thanks Helena Maher

## **APPENDIX 2 - INFORMATION FOR PARTICIPANTS**

Venue: St Michael's Hall, 120 Collins Street, City

**BACKGROUND:** The consumer movement emerged in the early 1960s with a focus on the importance of public involvement in decision-making in democratic society. Since the mid -1980's there has been increasing acceptance and even expectation that consumers have a stake in the development of health policy in this country. More and more, consumers are being called on to contribute to the planning, development, implementation and evaluation of health services.

Today's workshop will consider how to respond to these requests for consumer participation, how to ensure that there is appropriate and effective representation of consumer concerns and priorities and how to resource and support consumers involved in these processes.

**AIM:** To identify opportunities to develop partnerships, between consumer organisations, health service providers and consumers, that will build consumer and community participation in the health care sector.

### **QUESTIONS FOR DISCUSSION:**

#### Membership

- Who are the members of your organisation?
- What are the best ways of getting consumers involved in the health care sector?
- How do we ensure that consumer participation reflects the diversity in the community?
- How can Health Issues Centre increase the membership of its Consumer Nominee program?

#### Linkages

- How can Health issues Centre strengthen our relationship with your organisation?
- How do you communicate with your members?
- How can Health Issues Centre link the Consumer Nominee Program into these communication strategies?

#### Support

- What support do your members need to represent consumer interests and perspectives?
- How do you support your members?
- What can Health Issues Centre do to resource and support consumers in your organisation?

## **APPENDIX 3 - WORKSHOP PROGRAM**

8:45 am	Arrival: (Collect you name tag; tea & coffee will be available)
9:00	Acknowledgement to Country - Lisa Thorpe: ATSIC Regional Councillor
9:30	Welcome from Health Issues Centre - Meredith Carter: Executive Director
9:40	Overview of the Workshop - Maria Dimopoulos: Facilitator
10:00	Review Of The Consumer Nominee Program At Consumer Health Forum: Helen Hopkins, Executive Director, CHF
10:20	Questions
10:30	DHS Perspective On The Consumer Nominee Program - Mary Draper: Manager Effectiveness Unit, DHS
<b>10:45</b>	<b>MORNING TEA</b>
11:00	Membership, Diversity and Participation - Tanja Bahro: Centre for Culture Ethnicity & Health
11:15	Working with Marginalised Consumers - Meg Gulbin: Absolutely Women's Health, RWH
11:30	Consumer Advocacy - Wanda Bennetts: Consumer Consultant, North West Area Mental Health Service
12:00	Brainstorming the Issues
<b>12:30</b>	<b>LUNCH</b>
1:00 pm	Video: The Solution Oriented Mind Set Three themes for Discussion; Membership, Linkages, Support
1:15	Group Work
2:15	Reporting Back & Making Recommendations
3:15	Evaluation, Activities & Follow-up from Today's Work - Meredith Carter
3:30	Close

## **APPENDIX 4 - EVALUATION FORM**

Thank you for coming and participating in this workshop. We hope that you enjoyed the work you did today, and found it interesting.

We would like to know if you thought the workshop was useful.  
(please circle)

Yes

No

If so, why

If not, why not?

(you might want to make comments in the following areas)

- Opportunity to develop new ideas about consumer and community participation?
  
- Opportunity to contribute to the development of Health Issues Centre?
  
- Opportunities to network with other organisations?

Is there anything else that wasn't covered today, that you think Health Issues Centre needs to address or could do to improve its Consumer Nominee Program?

Any other comments?

## **APPENDIX 5 - PARTICIPATING ORGANISATIONS**

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Absolutely Women's Health  
Arthritis Foundation  
Bayside Health  
Bayside Health Community Advisory Committee  
Tumbukka ATSIC Regional Council  
Campespe PCP  
Carers Association  
Centre for Culture Ethnicity & Health  
Children's Hospital  
Chronic Illness Alliance  
North West Area Mental Health Consumer Consultant  
Consumer Health Forum  
Council of Self Help Groups  
Council on the Ageing Victoria  
Dental Health Community Advisory Committee  
Department of Human Services  
Eastern Health  
Health Issues Centre  
Inglewood Community Health Service  
Inner South Primary Care Partnership  
Melbourne Health  
Murdoch Children's Research Institute  
Northern Health Community Advisory Committee  
Peninsula Health  
Peter MacCallum Cancer Institute  
Peter MacCallum Cancer Institute Community Advisory Committee  
Plenty Valley Community Health Centre  
Royal Victorian Eye and Ear Hospital  
Southern Health Community Advisory Committee  
St Vincent's Health  
Victorian AIDS Council  
Victorian Mental Illness Awareness Council  
Western Health  
Western Health Community Advisory Committee  
Women's Health Victoria  
Youth Affairs Council of Victoria

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## **APPENDIX 6 - LISA THORPE – RECOGNITION OF THE COUNTRY**

Firstly I would like to acknowledge the traditional owners of the country, and through them pay my respect to the land we stand on.

Good morning my name is Lisa Thorpe I am a descendant of the Maar and Gunai nations of Victoria.

The health status of Australia's Indigenous people must be considered within a historical context.

The events, actions and policies of the recent past had and continue to have a direct impact on the health and well being of Aboriginal people throughout Australia.

Under the UN Genocide Act, any one of the following constitutes genocide.

- The deliberate killing of people.
- Causing serious mental and physical harm
- Deliberately inflicting conditions of life that are likely to destroy a people.
- Deliberate sterilisation
- Forcible removal of children from one racial, ethnic, or religious group to another.

All of these acts were committed on Aboriginal people. The impact left on Aboriginal people today, ranges from poor emotional and physical health, suicide, poverty, deaths in custody, substance abuse, domestic violence, unemployment, loss of identity, self esteem, and high rates of incarceration.

The Aboriginal people of Victoria and N.S.W. have suffered rates of forced adoption and removal of children, higher than any other single minority in the world.

The introduction of foreign disease, massacre and poisoning, abduction, rape and exploitation were amongst the atrocity and devastation perpetrated against Aboriginal people.

Aboriginal people can expect to live, on average (15-20 years) less than other Australians and experience higher rates of morbidity and mortality from almost every illness and disease. Death rates within the Aboriginal population are higher than that of other Australian's for every age group. Between the ages of 25-54 years, the death rate amongst Aboriginal people is 5-7 times higher than that of other Australians. Diabetes alone is 17 times more likely to affect you if you are Aboriginal. Maternal death is uncommon in Australia however, more common for Aboriginal women who represent 30% of all maternal deaths nationally.

Mental health incorporates the individual, family and community as a whole. This does not just refer to the absence of mental illness. It includes opportunities to express and develop emotional well-being in a safe and respectful environment. Exposure to ongoing poverty, discrimination and the history of racism experienced result in Aboriginal people being more vulnerable to mental ill health. "Psychological distress, especially depression associated with unresolved grief, ongoing losses and post traumatic stress is a major public health issue for Aboriginal communities and related to the position of Aboriginal people in Australian Society".

Data collection regarding people who are of Aboriginal origin is carried out in an ad hoc manner in many institutions throughout the state of Victoria. This has serious ramifications for the planning, resource and delivery of health services for Aboriginal communities.

The little statistical information that does exist on Victorian Aboriginal health rarely provides gender specific information (other than pregnancy or reproductive health related data).

Aboriginal community services exist because for many Aboriginal people, there are few alternative services that are considered to be safe, sensitive and responsive to their needs. Without the services provided by Aboriginal community organisations, many Aboriginal people would be excluded from non-emergency health care completely.

The development of specific strategies and services, driven by Aboriginal communities is critical. The need for such services is not based solely on whether tangible differences in culture, customs and traditions exist or not, but the connection mainstream services hold with the past. The entrenched institutional racism that is evident in many mainstream health services and justifiable fear and mistrust prohibits Aboriginal people's access into mainstream services.

For Victorian Aboriginal women, home, family and community life and obligations play a crucial role in maintaining and strengthening identity and belonging within their Communities.

Aboriginal women commonly express concern about men's and children health, which is regarded as a vital component of achieving their own health and well-being. Approaches to Aboriginal women's health issues must not cancel out the importance of children's/men's programs but must compliment each other.

Environmental health encapsulates the physical, emotional, spiritual, social, political and economic factors that impact on Aboriginal women's lives. Poor opportunities for housing, employment, educational and financial independence have direct implications for the day-to-day health and well being of Aboriginal people. This lack of opportunity can be seen in the main as a product of racism and marginalisation.

Addressing racism and racial discrimination requires long-term solutions and genuine commitment. Resolving these inequities is however fundamental to achieving sustainable and effective change to improve Aboriginal peoples health & well-being. Without this the third world health and living conditions of Aboriginal people will be maintained by the society of a nation built and existing on racist foundations.

## **APPENDIX 7 - HELEN HOPKINS - ACHIEVING GOOD PRACTICE IN CONSUMER REPRESENTATION**

### **Consumers' Health Forum of Australia**

#### **Consumers' Health Forum**

##### **National, peak organisation**

100 voting member organisations:

**Population** - older people, women

**Illness** - diabetes, asthma, arthritis

**Health interest** - State and community groups, carers

#### **CHF Aims**

- Contribute to improving people's health and well-being
- Represent the views and interests of consumers at a national level  
(from CHF Strategic Plan)

#### **Consumer Representatives**

- Protect the interests of consumers
- Present how consumers feel and think Contribute the consumer experience
- Ensure consumers' concerns are recognised
- Are accountable to consumers
- Provide information, report back

#### **CHF Consumer Representatives**

- Call for expressions of interest - newsletter
- Consumer representative nomination form
- Endorsement by member organisation
- Selection - Consumer Reps Subcommittee
- CHF agreement with consumer representative
- Consumer representative reports back
- CHF provides support and networking

#### **Review of the CHF Consumer Representative Program**

- 9 to 93 consumer representatives since 1987
- 30 committees in 1990 to 180 in 2002
- Steering Committee: 3 areas of Department of Health and Ageing; CHF Secretariat, Board, consumer representative
- Telephone interviews & focus groups for consumer representatives and Departmental committee secretariats  
*Chalkley Consulting with Artcraft Research 2002*

#### **Review Findings**

- Aims and objectives met appropriately, efficiently and effectively, but constraints on training

- Increase in size of task not matched by growth in CHF resources
- Opportunities for improved communication between CHF and its consumer representatives and the Department

### **Recommendations - DoHA**

- Resource the services of CHF
- Develop a consistent consumer representative policy: - finding accountable consumer representatives, sitting fees, reimbursements, special needs, accountability needs
- Train staff about consumer participation

### **Recommendations - CHF**

- Training for consumer representatives - package, workshops, resource kit
- Strengthen accountability procedures – feedback to reports, distribution, performance feedback mechanisms
- Develop policy resources
- Better response to urgent requests, information about selection, accountability

### **Developing a CHF response**

- Consumer Representatives Workshop
- Consumer participation today
- Benefits, trends
- Purpose of consumer representatives
- Challenges and strategies
- Training and support
- Policy development and update

### **Fundamentals for good practice**

- Ensure tokenism is not the approach used
- Recognise individual and collective input
- Focus on individual and societal consumer health outcomes
- Refer to broad social health framework
- Robust and consistent policy framework
- Ongoing training and support network
- DoHA and CHF partnership, commitment

### **Strategic Framework for CHF**

- Policy framework for consumer representation – DoHA and CHF
- Recruitment and support – CHF
- Health policy development, analysis and advocacy - CHF
- Performance and effectiveness – CHF
- **ACTION PLAN**

### **Further information**

- CHF Guidelines for Consumer Representatives
- CHF - Achieving good practice in consumer representation - [www.chf.org.au](http://www.chf.org.au)
- National Resource Centre for Consumer Participation in Health - [www.participateinhealth.org.au](http://www.participateinhealth.org.au)

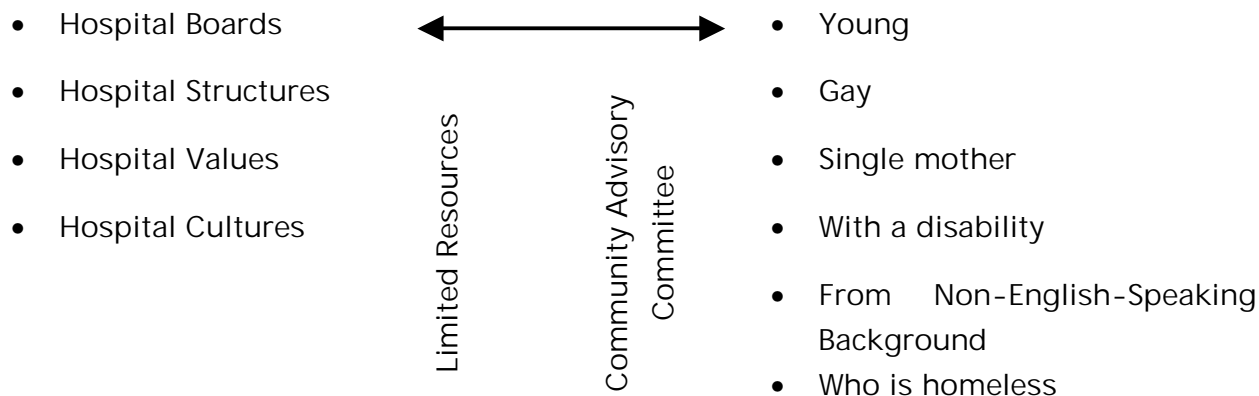
## **APPENDIX 8 - TANJA BAHRO - MAKING WAVES**

### **Membership, Diversity and Participation in Acute Health Acute Care Diversity Collaboration Centre for Culture Ethnicity and Health**

#### **Overview**

- Representative Participation in Planning?
- Influencing Change in Hospital Systems?

#### **The Diversity challenge**



#### **Membership**

##### People with:

- A place to live
- Time
- Enough money not to worry about it
- English proficiency
- Assertiveness
- Familiarity with Anglo-Australian Systems

#### **How do we solve it?**

##### Membership

- Advocating for diverse Membership on Hospital Boards
- Payment and training for CAC members
- Portfolios on the CAC

#### **How do we solve it?**

##### Participation

- Real structures for feedback
- Implementation of feedback findings
- Informing communities

**And all lived happily ever after.....**

## **APPENDIX 9 - WANDA BENNETTS - MAKING IT HAPPEN**

### **From Policy to Picture Books**

#### **15.11.02 (Health Issues Centre)**

Thanks for inviting me to speak today. I actually gave this same presentation a few weeks ago, which is a bonus, as I usually don't get to do the same thing twice. When I was first asked to do this, I was also asked to think of a title for the presentation and let admin know the next day. That was a hurdle as I usually name my papers really boring things like, 'Presentation for this conference' or 'presentation for that workshop'. As I didn't know what I might say at the time of giving a title, I came up with this one, hoping it would be broad enough to capture whatever I ended up wanting to say. When I sat down to write, I realised that the topic I had chosen actually says a bit about me and who I am. The 'Making it Happen' bit is a reflection on my impatience for change. The 'policy to picture books' part says as much about my interest in diversity as it does about the possible breadth of the consumer consultant role itself and the 'picture books' bit is a hangover from a different life when I was a primary teacher. I am going to ask you indulge the primary teacher in me a little this evening as I walk you through my experiences over the last twenty-one months as a consumer consultant.

I would like however, to begin just a little before that and will start with one of those picture book stories. I'm sure everyone here knows the story of 'The Three Little Pigs' right? Who is the bad guy is in the story? It is of course the 'Big Bad Wolf'. I'd like to ask you all how you know that the wolf is bad and the pigs are good. (audience response?) I'm sure it is because of what the story tells you he does and we have all been told that version of the story from the time we were very small and it is now well ingrained knowledge to us. Has anyone heard the wolf's account? Well, I have a story here that tells the wolf's version of events.

(Summarise story – The True Story of the Three Pigs!, Jon Scieszka, illustrated Lane Smith).

This story illustrates for me, something that is easily forgotten – perspective. We often think we know a truth, but it can be a one sided truth. And we don't ever question things when we know them to be right.

I began my work in consumer participation knowing my truth. I desperately wanted people in my life and in mental health to understand that truth. I didn't know the theory behind what I was about to do or what the work was really about. I just knew that the nurse who had looked after me when I was very unwell (and who is now a good friend of mine) had said that I made a difference and that she understood things differently after talking to me. And, I happened upon an add that intrigued me when I was looking for a new job. That add was answered and I interviewed appallingly, but that add and interview changed my life. I began on a 'no return journey' and the destination was consumer participation. I wanted quite badly to become a consumer consultant, because the add I had responded to had conjured

up an idealistic opportunity that would allow me to tell my truth and maybe even to help others to tell their truths – to get the perspectives of consumers out there and accepted. I set about learning and working towards that goal, which, as you can see, I eventually achieved. I had no idea that there was any other way to work in CP.

The first position I took up was a very gentle and positive step towards a job as a Consumer Consultant . It was in a Psychiatric Disability Support Service, where staff and consumers of the service had spent a great deal of time preparing for CP in the service. I did that for a day a week for about a year. It was quite a reality shock and very puzzling when I started nine months later in the clinical setting and realised that although some staff were very welcoming of the role, there were also people who didn't like or accept the whole notion of CP. But, I put that aside and found it was also extremely exciting and new and interesting and wow, fancy being paid to open my mouth and have an opinion on everything. It seemed like a job just made in heaven for this mouth of mine. I plunged into things without really knowing where I was going. I met some great people (particularly consumers), and I tried to learn as much from them as I possibly could (and continue to do so). I read a great deal. If asked to do something, I always said 'yes', even though I wasn't sure that it was the best thing to be doing. I figured I really didn't know what I should be doing and couldn't know until I had a sense of the possibilities and the only way to get a real sense of what was happening was to plunge in neck deep. Even the meetings, which included meetings such as Quality Assurance, Executive and staff meetings (that attendance at, does not, in itself mean CP is happening), were a great source of knowledge and often provided me with opportunities to open up informal discussions that led to some informal education. Education has always been and will always be a passion for me and probably one of my main interests in this work.

Over time I have learnt quite a bit about the service from 'the other side', but the important work has been learning from other consumers. One of the best parts of the job is getting to meet, speak with, know and work with many other consumers. There are some amazing people out there. The main opportunity to do this is by going down to the ward and speaking with consumers in the inpatient unit. I do this as often as I can, although my co-worker does this much more often than I do. Working with members of the consumer advisory group and chatting with consumers in the waiting rooms at the clinics has also been a good way to hear what is happening for consumers at a given time and all that can be learned from these interactions is fed back to the service, with the goal of 'change for the better' always there. The other great opportunity that I get as a consumer working in CP is getting to work with others doing the same or similar work. An example of this was the exciting preceptorship project that I was lucky enough to be a part of last year, with Cath Roper, the consumer academic at Melbourne University. In this project, consumers were preceptors for the post graduate nurses for an hour a week over about seven weeks.

The variety in the work is one of the really positive things about the job. As the title of this presentation implies, the work of consumer consultants can range from the

more mundane such as policy right through to being involved in projects. The work in policy development is however, still important. Although having something in policy doesn't mean it will happen, it's always helpful to have the policy in place anyway. In some instances, it actually can be the catalyst for change. When I first raised the issue of being involved on staff selection panels, I used the policy document that referred to this issue under the definition of what a consumer consultant can do within the policy. It was taken as policy and some movement in the right direction occurred. A pedantic point however was made around it being part of the definition and not actually policy a month or two down the track when an adversary questioned it. He used this as a sign that he did not have to include consumers on panels from that moment, as it was not policy.

While on the subject, interviewing has been an interesting and both positive and negative experience as well. It not only gives an opportunity to have input into the selection of good staff, it also provides a great educational forum. On the surface, it makes a statement to the interviewees that CP is important and often helps to make a connection with new staff once they are on board. I was however, a little dismayed after one interview. The discussion was that one of the applicants may tend to 'treat all staff like consumers' and it was said with abhorrence that "Staff don't like to be treated like consumers". My immediate retort was that consumers don't like to be treated like consumers either, to which I was given some rhetoric about consumers giving permission to enter into a therapeutic alliance, so it was OK, but the comment, "Point taken", was added. I very much wonder however, how much it really was understood .

As I said earlier, education is my passion, both in the sense that I like to keep learning and I like to be an educator. There have been a lot of opportunities open to me and I started with some IT workshops to try to get over my fear of computers and technology, although I have to admit that I still have regular fights with computers, photocopiers and fax machines. My husband tells me that they play up on me because I abuse them and don't talk nicely to machines. In my line of work I need to be careful about being seen talking nicely to technology, although I did witness a member of the CAT team threatening to certify the fax machine some time back.

I attended some workshops open to clinicians mainly to get a sense of what they were being taught, but as I have never been able to just sit quietly and observe, I usually find my mouth open for comment very early in the day. I have been quite pleased to be asked to deliver some consumer perspective sessions at a few of these workshops since and I think this opportunity will increase for my colleagues and I in the future at North Western Mental Health. The same opportunity has come up at symposiums and the like and hopefully the input of consumers at these has helped to challenge people's thinking.

Encouraging for me when doing this sort of thing has been the response I have had when raising the concept of 'constructive non-compliance' and I hope that I have been gauging it accurately when I sense that a light has gone on for a few people

and that they are reflecting on this notion and starting to consider it in a different way. I started to talk about this a while back after reading an article by Sally Thorne (1990).

She notes that for compliance to occur, two parties must be involved – one to give an order and one to follow or not. And yet the literature and discussions I have heard, seem mainly to reflect compliance from the perspective that it is all about consumer compliance, with suggestions and strategies on how to achieve this. There is little or no attention paid to the role of the professional in non-compliance. So, what is compliance?

Is it taking medication and doing what someone else decides is good? Is it not asking questions?

Is it surviving? In the article by Thorne, (mentioned above), non-compliance is revealed as a deliberate and conscious strategy that demonstrates an understanding of the power structures within healthcare. It refers to consumers modifying treatment, being selective about what they choose to adhere to and so on. And it also explores the reasons behind this. Feelings of empowerment with the self as 'expert' are prominent with people in this study who were seen to be and self declared as non-compliant. Non compliance was seen as a positive thing with themes of self protection and maintenance of health care relationships among the reasons, as were significant acknowledgements around quality of life.

Benefits of non-compliance were seen as increased confidence, as well as increased consciousness of the limitations of the healthcare system. There was also a correlation made between the amount of responsibility taken on by consumers as their compliance levels dropped. Overall, non-compliance in this article was seen as a positive thing and even something that increased rehab as the consumer was seen to be taking more control and achieving better results. This is in stark contrast to the way I have heard clinicians talking about, compliance where the authority and power lay in the control and unquestioning acceptance of treatments offered and the pathologising of the consumer who does question and does not comply. It's an interesting topic to raise and the fact that it has started some discussions and made people think about how they see this has been one of things that has helped me to think that maybe I can have a positive influence on practice.

The projects that come up are a good proactive way to contribute to CP. The amount and level of input has varied. Sometimes it has to do with how much I have been asked to contribute and sometimes it has simply been about how much time I have been able to give. One of the goals for next year is going to be how to get the service to include more consumers if the service, involved in a more meaningful way. Hopefully, as staff become more used to having consumers involved, slowly but surely, working with all consumers in the service will just be a way of 'doing' and not an 'add on'.

One of the things that I have really enjoyed is doing presentations like this, although I do get quite nervous and tend to talk a bit too fast. The first time I used a picture book to make a point was when I gave a presentation and I was trying to think of a

way to finish off. These days I think children's books are as much for adults as they are for children. I wanted to talk about the therapeutic quality of relationships and I remembered a beautiful picture book I used to read at school – Wilfred Gordon McDonald Partridge. It's a story that demonstrates the powerful and rehabilitative impact that comes about as a result of relationships. This book is about Wilfred Gordon McDonald Partridge, who is a little boy ("who wasn't very old either") and he lives next door to a nursing home. Wilfred makes friends with all the residents, but his favourite person is Miss Nancy Alison Delacourt Cooper, because she has four names, just like him.

Wilfred gets a little concerned when he hears that his best friend, Miss Nancy, has lost her memory and he sets about helping her to find it. But, first of all he has to find out what a memory is, so he asks everyone he sees. In response to the question, "What's a memory?", he is told that it is something from long ago, something warm, something that makes you cry, something that makes you laugh and something as precious as gold.

Wilfred looks for memories, because Miss Nancy had lost her own and he sets about finding objects, including a warm egg from the hen house on his way in to visit Miss Nancy. As he hands each item to her, she begins to remember and they talk and laugh. It's a story I have enjoyed sharing many times since, because it is such a beautiful story about relationships and seeing the person and not the illness. Trying to hear as many voices as possible has been quite a challenge, and we developed a survey this year. It was based on something from the Sainsbury Centre in England, but was turned into a survey as opposed to an interview. We added to it and adapted it after discussions and a trial with the Consumer Advisory Group. What was exciting about it was that we had the chance to lead this – to ask the questions we thought were important, but we were offered help from staff to do it. Admin staff typed up and reworked several drafts and helped with the layout, seniors and managers supported the concept without trying to muzzle in and change things, staff helped with the implementation stage and one of the senior staff offered to set up a computer analysis so that we can generate some more organised and flash results to go with the final write up which is in progress at the moment.

Getting back to my work as a Consumer Consultant there has been a lot of naiveté and that has added to some distress at times. I would be remiss if I didn't talk about some of the real difficulties and struggles I have had as well. This work can take a personal toll and if not for other consumers and supports, it would be almost impossible to do at times. In this job, I have found I constantly question myself. One of the real toughies for me has been around getting positive feedback. Like others, I just love the positives. The paradox in this work is that the compliments may come because I am 'safe'. I have to ask myself each time someone tells me I'm doing a good job, is it because I am not too challenging for them and therefore 'safe', or has that compliment come because I have made a real connection, worked hard and earned the respect of that person?

Another difficulty is the adversarial nature of some of the work. As someone who has always avoided conflict, this can also be quite difficult and, as a consequence, I tend to look for ways that I can work in a more proactive manner, working with people who are supportive of the role and see the contributions of CP as enriching, rather than a negative. This means however, that I sometimes avoid working where the need is greatest.

Becoming too emotional can also be a trap for me. It is recognised that this work can be extremely difficult when things tug at emotions or trigger something for a past or personal experience. I know I certainly can't switch it all off and I may even become quite concerned if I could. However, I have recognised that my personal style and impact is diminished when I become too emotional. I become less able to get a point across clearly and therefore, am less effective, but even more difficult is the personal toll it takes on my emotions. I am also aware that I am being judged as a 'consumer' and although it shouldn't be this way, it does make a difference to the credibility afforded to me and to my self esteem and it seems to give some people an excuse then to be dismissive of what I have to say or to personalise situations. Fortunately it's not something that many people do, but it has been an incredible struggle on a few occasions when it has happened.

The hardest of all to deal with however, is the oppression of a system that I know can and does make things worse at times. It is almost impossible sometimes to handle. I sometimes see and hear things that make me cringe or worse still, make me feel sick. I know that they are for the ease of the system and not for the benefit of consumers and I feel totally useless, frustrated angry and sad. I also know that to raise them will only bring on annoyed justification and explanations and that I will never ever be able to change how some staff think and work. I still do keep raising things which is immensely difficult, but I find that I also withdraw from those situations and people in order to survive so that the environment doesn't become personally toxic as well and that is not something that feels good at all.

However, twenty months down the track, I can say that the excitement is still there. I don't have two days the same, let alone two weeks or two months. I am still on a steep learning curve and it seems that there are new and interesting opportunities sitting there just waiting to be put into action. Next year I hope to get an opportunity to do a project around debriefing or 'empathy briefing' as I have heard it called for consumers. I'm not at all sure what that may look like yet. I have just finished the training for that and I have spoken casually about it to a few people who have expressed some interest in supporting the idea.

I have good and bad days like everyone and on my bad days, I ask what is different for consumers of our service because I have been in this job and answer a depressing 'nothing'.

On my good days, though, I think about the story, *Because a Little bug went Ka-Choo!*, by Rosetta Stone, (illustrated by Michael Frith). In this story, a little bug sneezed, causing a seed to drop that hit a worm and the worm got mad. In his temper the worm kicked a tree which made a coconut drop, which bopped a turtle

on the head and so on and so on, causing great chaos. It ends with a spectacular circus parade and, "That started something they'll never forget. And as far as I know it is going on yet". And all this was because a little bug went ka-choo. I'd like to think that my contributions cause a ripple effect. Although not obvious immediately and to everyone, (the bug was not aware of what it had started), I hope that one day, something I do will create that chaos and have an impact that will last forever and that nobody will forget. We all have to dream.

Thanks for listening to me.

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