

Setting Up a South Australian Consumer Health Organisation: Outcomes from the *Healthy Voices* Consultations.

Prepared by John Wishart
Healthy Voices Project Coordinator.
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A. Introduction

South Australia has no statewide consumer health organisation. Volunteers working in small poorly resourced groups or as individuals carry on much of the consumer and community advocacy, support and representative work. In comparison to health professionals and health providers, consumers and community members have great difficulty being heard and influencing health planning and services. The main barriers to effective participation are well documented. These are summarised in *Building Effective Consumer Participation*, June 2001, attached as Appendix A.

Many consumers, carers, community organisations and providers interested in health issues consider that a state based consumer organisation would be a valuable and much needed means of ensuring more effective participation for health consumers.

This Report is written as a guide for the Preparatory Committee that will establish a new broadly based consumer health organisation in South Australia. It distils discussions, resolutions and working papers that the *Healthy Voices* Project has facilitated over the last twelve months. In particular it builds on the proceedings of the *Raise Your Voice* Conference held on 19 October 2001, the Discussion Paper entitled "What Do We Want the New South Australia Consumer Health Organisation to Look Like?" (March 2002) and the feed back on this Paper over the last two months. More details about the consultative process are contained in Appendix B.¹

The Report sets out principles, aims, objectives and proposals on structure for the new health organisation. In the main these record the common ground coming out of the consultations. But quite naturally there are areas of difference and ambiguity about what is wanted among the many people and organisations that have been part of the process. Building any grass roots organisation is an evolutionary process where priorities and structures change over time. For these reasons the Report should be read as a guide to assist in setting up the new organisation rather than a blueprint to be implemented in an inflexible way.

B. Some key terms and concepts.

Health --- "health" is taken to encompass well being and illness. A person's health status is a combination of individual, social, cultural and environmental factors. We follow a "social health" perspective in the tradition of the World Health Organisation's three landmark documents: the Declaration of Alma-Ata 1978, the Ottawa Charter for Health Promotion 1986 and the Djakarta Declaration 1997.

Health Consumer—an individual who uses or has used a health service. We use the term to include carers.

¹ Thanks go to the many people who have participated to date in numerous ways. Special thanks go to the people who have assisted on working parties, given presentations and helped with the logistics of the October Conference and the subsequent consultations and meetings. Most of this work has been voluntary.

Carer- a person who provides care and support for their parent, partner, child or friend, who has a disability, is frail, aged or who has a chronic mental or physical illness.

Participation—the process of involving health consumers (individually or through groups/organisations) in decision-making about their own health care, health service planning, policy development, priority setting, health services delivery and evaluation of services.

Peak Body---an organisation with other organisations formed to represent the collective views of its members to government, to the community and to other bodies”.

C. Principles Underpinning the New Organisation

Participants want to see an organisation which

- Is owned and controlled by health consumers and consumer health organisations
- Is responsive to individual consumer concerns
- Undertakes systemic advocacy but pursues individual concerns in the absence of other avenues
- Is consumer friendly
- Consults with its membership prior to decision making
- Obtains feedback from its members and ensures this feedback is used to improve services.
- Is democratic and transparent in its structures and decision making processes, including elected officers being accountable to the general membership
- Is independent in its policies and decision making
- Is financially and organisationally strong and sustainable
- Is accessible to all (eg in membership fees, structures and decision making processes)
- Gives priority to less powerful population and social groups which are in greatest need of an effective voice.
- Represents the cultural and linguistic diversity of South Australia’s population
- Gives a clear weighting in voting to representatives of health consumer organisations and health related community groups over individual members
- Forges alliances with other groups and individuals on issues of common concern and interest.
- Pursues collaborative working relationships with other organisations and agencies consistent with the aims and objectives of the organisation.

D. Aims of the New Organisation

The following aims were very widely supported by participants:

- To provide and support an effective, sustainable and independent voice for consumers in the South Australian health system.

- To encourage the consumers' role in the planning and development of broadly defined health services
- To enhance the capacity and promote the rights of all consumers to be involved in health research, policy, planning and service decisions and evaluation.

E. Objectives of the New Organisation

There is broad but not unanimous support for the following objectives.

1. To develop and promote health policy.
2. To lobby and advocate on health issues at the policy and systems level.
3. To encourage and support public discussion and debate about
 - Health legislation
 - Health issues
 - Health services and policy
 - Consumer and community participation
4. To consult with consumers and community groups in the development of policy and priorities.
5. To work for a strong independent and effective voice for consumers and community groups in SA taking into account the barriers that face people of specific cultures, ethnicity, location, age and gender.
6. To inform and educate consumers and community groups about health policy and legislation.
7. To provide education and support for consumers and community groups in their efforts to achieve beneficial changes in the health system.
8. To strengthen the voice of consumers and community groups in SA by building and supporting strategic alliances
9. To support and foster partnerships with health service providers which assist the participation and empowerment of consumers and community groups in the health system.

F. Membership criteria and eligibility

The principles set out in Section C should shape the rules governing eligibility for membership and decision making within the new organisation.

An essential requirement is that the new organisation is owned and controlled by health consumers and health consumer organisations. All people who live in South Australia are health consumers. Therefore the organisations should be open to all people to join who support the aims and objectives. However some restrictions are needed on what sorts of organisations are admitted as voting members to ensure

that the organisation develops and remains as a non-government, not for profit consumer controlled body.

The membership criteria below have been developed to reflect these principles.

Types of members.

1. Establish two types of membership: individual membership and organisational membership.
2. Establish two types of organisational members: voting and non-voting. Non-voting members could be called "associate members".
3. Associate members will not have voting rights in the organisation but they should be free to participate and enjoy other non-voting membership rights and benefits.

Admittance to membership.

1. Any individual may become a member provide s/he accepts and supports the aims and objectives of the organisation and pays the membership dues.
2. Any organisation may become a voting member provided the organisation
 - (a) Accepts and supports the aims and objectives AND
 - (b) Pays the membership fee AND
 - (c) Is not either
 - A commercial for profit health care organisation OR
 - A government health care provider organisation OR
 - A government department or statutory body OR
 - A government funded health administration organisation OR
 - An association/organisation of health or health related professionalsAND
 - (d) Has rules that provide for the ability to have at least two consumers represented on the governing body of its organisation as voting members.
3. Any organisation may become an associate member provided the organisation accepts and supports the aims and objectives and pays the membership dues.
4. The Governing Body of the organisation will admit members and associate members.

Voting rights

There was no consensus in the consultations on what weighting to give to individual and organisational voting members, although most people supported the principle that organisations should have a weighting in voting over individual members. A number of people were concerned about domination or controlled being exercised by the better resourced community organisations as compared to individuals. Others felt it reasonable to give organisational voting members multiple votes---say 2 votes each.

The Preparatory Committee will need to determine this issue.

Who and How many people will be on the governing body?

The consultations did not produce any proposals on this question. It will need to be determined by Preparatory Committee.

G. Type of Organisation.

The Discussion Paper (March 2002) canvassed four models for the new body: "peak consumer body", "membership model", "peak non-government organisation" and "peak forum". There was almost unanimous support for the first model of peak

consumer body. The attributes of this type of organisation as they appeared in the Discussion Paper are:

- Individual consumer membership
- NGO membership
- Associate membership for service or non-consumer based organisations
- Governance body constitutionally weighted to include individuals, organisations and representatives from disadvantaged groups
- Ability to approach unrepresented groups for advice or “secondment” to governance body membership in order to address specific issues.
- Provides systems advocacy, training and support for consumers and consumer organisations, information, advice to departments and the like.

The perceived advantages of this model were seen as

- Autonomous, independent consumer voice
- Representative membership
- Agenda set by consumers
- Consumer and NGO focused

The disadvantages people listed in feed back on the Discussion Paper were :

- access to funds
- dangers of cooption or erosion of independence if funds were provided by other organisations or government
- danger that the new organisation might take over or duplicate the work of existing consumer and community organisations.

Most people did not want the new organisation to be a “pure peak “ body sitting on top of a hierarchy of existing consumer groups. Rather participants wanted a broadly based state organisation which was composed of individuals and organisations which added value to the work of existing organisations and which took up health issues and priorities of a systemic nature which were not able to be pursued strongly at present. The membership criteria and categories listed above are consistent with this position.

Some participants suggested that the new organisation might consider developing a decentralised structure of sub-groups where local/ regional and or population groups form and feed into the state body. For example a number of metropolitan, regional. Indigenous and youth groups could be established and link into an overarching state council or forum.

H. Relationship between “consumers and “providers”.

Considerable debate has occurred on this question and no consensus emerged. Some participants take the view that the organisation should be arm’s length from health providers while others argue that partnerships are essential for change and that it is appropriate to actively and openly engaged providers who are committed to strengthening consumers health participation. Underlying this debate is the historical power imbalance between health professionals and consumers and the tendency for the more powerful groups and individuals to take over or subvert the goal of consumer sovereignty. It also is related to who is deemed to be a “genuine” consumer, with a minority taking the view that the real health consumers are the

people with specific illnesses. Other participants have made the point that some individuals and groups are not able to speak for themselves and require temporary or more permanent advocates. Some health providers currently fill this role. Examples include young children, some newly arrived refugees and some people with disabilities.

A clear majority of people involved in the consultative processes favour the formation of strategic alliances between consumers and providers. For example the Conference Direction Statement, October 2001, endorsed "strong partnerships between consumers and providers" as one of the necessary ingredients of effective and meaningful consumer, carer and community participation. The underlying principles and the proposed membership criteria outlined above are consistent with this perspective.

I. Evolving Process and Priorities

The above is a distillation of the views of participants in the consultative process to this point in time. Priorities and processes will evolve as the new organisation is established and develops. What can be tackled, and how effectively, will depend on the degree of unity, the quality of leadership and resources generated. A number of participants have acknowledged that the aims and objectives are ambitious and that it is important to start small with what is manageable and achievable.

What is clear is that there is no shortage of issues and tasks that a new body could take on if resources were available. For example, a general meeting convened on 5 December 2001 to discuss ideas for a state based consumer health organisation came up with a long list of possibilities (See Appendix C). Substantial progress on a number of these will require sustained funding and the consolidation of a well-run organisation with broad community support.

APPENDIX A Barriers to effective consumer participation.

(extract from *Building Effective Consumer Participation: A Discussion Paper Prepared by the SACOSS Consumer Participation Project Strategy Group, June 2001.*)

BARRIERS/PROBLEMS INHIBITING EFFECTIVE CONSUMER PARTICIPATION.

Commentators have identified a series of barriers that inhibit effective consumer participation. They include: -

- **Health consumers are less powerful**

A fundamental power imbalance between health providers and health consumers. Most of the knowledge and power about health planning, expenditure and mode of health service delivery is in the hands of powerful elites in the public and private sectors. Large private companies, well resourced professional associations, government ministers and high-ranking public servants have most of the power when it comes to the health system. Even at the doctor patient level, the consumer is rarely on an equal footing with the professional.

- **Health consumers are usually fragmented**

Consumers often have different interests and needs surrounding illness and well-being depending on age, income, location, ethnicity, gender, specific health status and so on. Although we are all potential users of various health services, at any one time each individual has no need of most. Even on the question of health insurance-- - an issue for all citizens--- we have a dual public/ private insurance system with consumers having different interests based on their health needs, income, their individual perceptions about health care and where their health dollars have been invested.

- **Systemic constraints on health providers**

During the last decade funding for many health services has been tightened. There is often very little room to allocate staff time and other resources to fostering genuine partnerships with health consumers. There has also been a retreat from a participatory workplace culture. Staff sometimes fear reprisal if they speak out about inadequacies in service planning or delivery. These constraints make consumer participation and partnership more difficult.

- **Lack of commitment by health providers**

Despite the many health providers who are committed to improving consumer participation, it remains the case that many health planners and providers are not committed to sharing power with health consumers. Instead of a real partnership, in practice this can lead to tokenistic consultation with consumers or co-option of consumers in furthering the agenda as determined by the planners and providers. The consumer is seen but not heard, or heard but not listened to.

- **Lack of resources for consumers**

Consumers often lack access to information, to training, to money and to networks that are necessary if they are to enter a meaningful partnership with health providers and planners. This is especially so where consumers are working as representatives on committees. Consumer representatives usually are expected to sit on committees

as unpaid contributors working alongside professionals who attend in paid time and whose meeting and committee expenses are fully reimbursed. Consumers fulfilling a representative role often feel isolated and without a sustaining support network.

- **Most in need are often most marginalised.**

Those groups who have the greatest ongoing health needs--- the poor, the aged, the young, people from linguistically and culturally diverse backgrounds, disabled, indigenous, rural and remote, chronically ill ----usually have the weakest voices as consumers. Many from these groups do not have basic knowledge or access to existing health services. Health services are often not culturally appropriate. It is a challenge to ensure access to services for these groups and opportunities and structures where representatives can effectively participate.

- **Health care consumers are sick.**

Our health care services are really sick care services. Unlike consumers of most commodities, no one chooses to be in a position where they need to use sick care services. Usually when they do they are ill and their very illness limits their capacity to make well researched judgements about the services they use, or to be optimally involved in their own care and treatment.

- **Problems of accountability, representation and legitimacy.**

The role of the consumer representative can be fraught with difficulties. To whom and how is the representative accountable? This can be unclear and sometimes the representative represents no one other than himself/herself. Does the representative have the resources to gather the views of his/her constituency and report back to members? Often not. If the rep is not "properly" trained they can be viewed as amateurish. If on a number of committees the representative can be lampooned as a "professional consumer representative".

APPENDIX B CONSULTATIVE PROCESS LEADING TO THE REPORT

The Report is based on key consultations, meetings and workshops undertaken by the Project over the last 12 months. These include:

1. Preparation of a discussion paper by the SACOSS Consumer Participation Project Strategy Group entitled *Building Effective Consumer Participation*, June 2001.

This Paper is available on the SACOSS website at [www.sacoss.org.au/projects/health and community services consumer participation project](http://www.sacoss.org.au/projects/health%20and%20community%20services%20consumer%20participation%20project). The paper was informed by a range of key interviews with consumer activists, researchers and professional health workers.

Membership of the Project Strategy Group was:

Jocelyn Auer, SACOSS Health Policy and Advocacy Group, Storey Chambers, SACOSS Policy Council, Margaret Charleton, Consumers Representatives Network, Alwin Chong, Aboriginal Health Council, Truus Daalder, Council on the Ageing, Anne Johnson Department of Public Health Flinders University, Robyn Miller, Health Rights and Community Action, Jai Milner, Youth Affairs Council of SA, Paul Laris, Friends of Medicare, Miranda Roe, PhD student University of SA, Clare Shuttleworth, Department of Human Services, Angelika Tyrone, Multicultural Communities Council, Fiona Verity, Department of Social Work, University of SA, John Wishart Senior Policy Officer SACOSS

2. *Raise Your Voice: Consumer Health Participation Conference*, 19 October 2001.

This was sponsored by the *Healthy Voices Project* and the SA Community Health Association. Attended by over 100 consumers and community representatives, the Conference endorsed the establishment of a state based consumer health organisation as the first priority. The Conference Papers can be found on the SACOSS website.

3. Specific Discussions on what kind of SA consumer health organisation was needed.

A General Meeting was called on 5 December 2001 using the *Healthy Voices* network. This meeting workshopped aims, objectives and possible activities. A Working Group was set up to take these ideas forward. The Working Group produced a paper entitled "*What Do We Want the New South Australian Consumer Health Organisation to Look Like?*" 13 March 2002.

Membership of the Working Paper was

Damian Amamoo, Jocelyn Auer, Sam Battams, Margaret Brown, Dimitri Calantzsis, Margaret Charlton, Charles Charlton, Elsie Fisher, Bev Freeling, Tina Griffin, Joan James, Paul Laris, Bob Leahy, Michele McHugh, Valerie McKeown, Pam Moore, Sue Pluck, Karen Richardson, Heather Spooner, Adrian Tonkin, Fiona Verity, John Wishart and Brian Wreford.

The Paper was further discussed at a General Meeting held on 27 March 2002. Fourteen individuals and organisations also returned written feedback on the paper in response to a mail out to the *Healthy Voices* network and other contacts.

Written feedback has been received from the following organisations

Alzheimer's Association, Anti-Cancer Foundation, Arthritis Foundation of SA, Barossa and Area Community Health Service, Consumer Reference Group---Western Domiciliary Care, Homebirth Network, ME/Chronic Fatigue Syndrome Society, and the Northern Metropolitan Community Health Service.

APPENDIX C—What should the health consumer organization do?
(Ideas listed by 53 participants in small group discussions, 5/12/01)

1. Provide individual and systems advocacy and link advocacy groups.
2. Encourage empowerment of consumers by developing partnerships with providers and a real voice in government and policy development.
3. Network and support, reaching out to individuals and groups who may not ordinarily be involved not only the 'converted'.
4. Consumer and provider forums, conferences, and workshops which encourage awareness and debate. Look at common issues for individuals and providers.
5. Lobby for and on behalf of consumers and providers.
6. Make health service providers accountable. Monitor and change poor practice.
7. To cover a broad range of issues of all views and objectives not only a selected few by a select few.
8. Resolve funding and resource issues.
9. Demonstrate advocacy for consumers and providers at all levels – individual and systemic.
10. Health education of providers and consumers
11. Encourage consumers to speak for themselves i.e.: independence.
12. Recognise when consumers do not need a spokesperson and support them appropriately.
13. Encourage the role of providers in the development of new organisations. Consider existing groups and providers as a resource.
14. Include Carer's.
15. Develop leadership that can facilitate inclusion and change.
16. Build alliances and opportunities for inclusion.
17. Education and empowerment through advocacy.
18. Policy development. Identify legislative teeth and recognition of the legitimacy of health consumers.
19. Broaden scope to include community health services.
20. Set clear attainable, objective, positive (health) outcome goals.
21. Don't take on too much too early.
22. Be consultative and develop of consultative processes.
23. PR to raise awareness
24. Encourage independence
25. Promote the legitimacy of health consumers voice.
26. Public relations
27. Independence
28. Promote the legitimacy of the consumer voice
29. Have a dual focus 1. Peak body, 2. An organization representing individuals and common interests.
30. Research and evaluation – issues based identifying gaps in service delivery and service practice.
31. Develop best practice and monitor services and policy.
32. Capacity building through advocacy to enhance the inclusion of marginalized group's i.e. chronic illness, youth, and indigenous groups.
33. Encourage equality vs. promoting difference between service user and service provider.
34. Present inclusive representation of views.
35. Structure weighted in the balance of consumers.
36. Encourage participation in planning.