A Guide to Effective Consumer Participation in Mental Health Services

MINISTRY OF
HEALTH
MANATŪ HAUORA

Introduction

This guide has been issued by the Ministry of Health for use by providers of mental health services including doctors, nurses, health workers, caseworkers and caregivers, providers of other services which are utilised by mental health consumers, and consumers themselves. This is a guide for practice within mental health services. Part of the service role is regular consultation with and involvement of consumers in decisions made abut the general running of the service.

A guide is considered appropriate because it is only relatively recently that input into service planning by consumers has been seen as appropriate and useful. Practices described in this guide are recommended because it has been shown that clear benefits to the services, their staff and their ability to meet consumers' needs result from consumer participation in service management.

The guide's first section explains why consumer participation is useful and necessary for effective management of services used by mental health consumers. In the second section, strategies to expand consumer participation are presented in detail. Finally, a list of consumer organisations in New Zealand, a recent literature review, and a sample checklist for consumer participation are appended.

Acknowledgements

Contents

1 Why Consumer Participation?

Note: this section describes why and how consumer participation in decision making has become accepted over the last decades.

1.1 Background to consumer participation

International literature and research conclusions over the last 15 years have shown unprecedented unity between consumer groups and mental health workers in calling for consumers to participate in planning, implementing and evaluating mental health policies and programmes. A literature review including many relevant international articles researched in preparation for this document is included at Appendix Two.

The major advantages of increased consumer input into mental health services are similar to the perceived advantages of increased contact between any service provider and consumers who use it. Increased consumer input, if carried out effectively, should lead to services that are more responsive to consumer needs. As a flow-on effect consumer involvement may diminish the costs of service operation, by 'getting it right first time' for consumers and by promoting consumer health through participation. It would also improve outreach and encourage development of more co-operative and less paternalistic treatment regimes.

1. **Efficient and effective services which meet consumer needs.** Resources can be better targeted if services reflect annual needs. For example, research has suggested that mental health providers and consumers often disagree when assessing consumers' needs. A lack of consumer input will lead to a lower quality of service for consumers.

2. **Ethical reasons.** People's ability to take responsibility and control over their lives is central to their quality of life. Providers should acknowledge that if they do not give consumers the opportunity as of right to influence and shape the services they receive, then the legitimacy of the service is questionable. This is because the human rights of the consumer to the greatest possible level of autonomy are paramount.

3. **Health reasons.** Participation by consumers in mental health services has been shown to be empowering to both the individuals and the organisations involved. Empowerment is defined as a process by which individuals gain control over their own lives and a sense of participation in their community. This process occurs gradually as a person becomes able to cope with and enjoy greater responsibility. Therefore, empowerment is an important health goal for consumers.

The traditional model. The past experience of consumers in mental health services is linked closely to the underlying model that dominated psychiatry prior to the 1960s. Traditionally mental health services have been based on a 'benevolent paternalism' model which assumes 'best interest' decision making by clinicians on behalf of consumers. Two concepts have kept this philosophy dominant in mental health services until recently: the 'authority of position' held by providers of welfare services; and the 'authority of knowledge' held by clinicians due to the

societal belief that only people with specific levels of academic achievement could make a useful contribution to the service sector.

This model of service has been the most serious barrier to consumer participation in the past. The result has been that many consumers, particularly those who spent periods of time in institutions, lack faith in their ability to assert control over their own affairs, or to represent others.

More recently, many of these assumptions have been challenged. The traditional model is unacceptable today in mental health services. Both providers and consumers recognise that each party has a valuable contribution to make.

> *'Much as in the civil rights and women's movements, consumers of mental health services are exercising a new-found consciousness, a new sense of personal dignity arising from recognition of their basic rights and the opportunity to participate in decisions that affect them'* (Valentine and Capponi 1989)

1.2   What is consumer participation?

1.2.1   Categories of participation

Consumers may have input into decision making for mental health services at different levels.

- The individual level – having input into the treatment and services they use as an individual.

- The organisational level – input into provider agencies and organisations.

- The policy level – contributing to policy development of purchasing or policy agencies.

There are three major ways in which consumers are involved in participation.

- Consumers join groups or networks, which become active in advisory and/or advocacy roles and are controlled by their members.

- Consumers, as individuals or in partnerships or groups, work together with providers, on mental health issues.

- Consumers set up or become involved in consumer-run and consumer-managed enterprises.

Participation by consumers in particular projects can also be categorised as 'proactive' or 'responsive'.

- Proactive – direct input into policy making by taking part in the decision making process.

- Responsive – responding to consumer satisfaction surveys or acting as advisers.

1.3   Barriers to participation

There are a number of barriers faced by both consumers and providers when they attempt to establish partnerships to consider mental health issues.

1.3.1   Barriers in the professional sphere

a   **Paternalistic attitudes.** Mental illness is seen by some as a condition treated by experts who make decisions based on their assessment of 'the patient's best interests'. Some providers may resist sharing their power, as this threatens the traditional (paternalistic) clinician/patient relationship.

b   **Disinterest on the part of professionals.** Some people involved in mental health service management do not consider that consumer participation is important or useful.

c   **Tokenism.** It is a barrier to effective participation if consumers' ideas are only accepted when they conform to the ideas and philosophies of the provider or policy group. If participation is successful, consumers will be able to see tangible benefits, either in changed policies, increased control for consumers or increased access to resources by them. It is common for only one consumer to be present on a board of experts. Consensus in the literature suggests that 25–50 percent of committee composition should consist of consumers. Consumer participation should involve a role that reaches beyond consultation so that there is direct input into decisions. Where a decision on representation is made by consumers as a whole, token representation is less likely to occur. A service can address tokenism by fostering proactive and responsive participation, using networks and partnerships across the three levels – individual, organisational and policy. Ensure that participation is comprehensive and ongoing.

1.3.2   Barriers in the consumer sphere

a   **Lack of self confidence.** Many consumers have a long history of institutionalisation and/or being cared for by another person. Many have been socialised to be passive, many have had a very narrow range of day-to-day experiences, and many have rarely been in a position of power. Consumers' credibility is sometimes questioned because of their appearance, their past hospitalisation or their ongoing separation from community life. Providers may have contributed to creating dependency among consumers in a number of ways. For example, providers may overly assist inpatient consumers to the point where they are left with minimal personal responsibility, and some staff may treat consumers in a patronising manner which diminishes their self confidence. Therefore some consumers have commented they have a habit of allowing other people to make decisions for them. A consumer may feel even more in a minority when working with providers if they come from a different ethnic or cultural background from those they work with.

b   **Unfair expectations.** It is important that consumers are allowed to participate on their own terms, and that they are comfortable with the level of responsibility they are given. Respect for health and other needs should be given on the basis of equity for all members of working groups. Education and training will also assist consumers to be effective participants.

c   **Distrust of professionals and of a consumer participation process.** Some consumers have a basic distrust of clinical staff and fear placing themselves in situations where providers may dominate them. Consumers may be apathetic, suspicious or apprehensive about participation when services have been provided to them for so long without any opportunities for discussion.

d   **Poverty and lack of transport.** Lack of financial resources inhibits consumer involvement.

1.3.3 Barriers within organisational structures

a   It requires a considerable shift in attitude for consumers and providers to move beyond the traditional 'carer/client' relationship, and treat each other as equals. This has been described as 'role strain', as the roles involved in a working partnership arrangement are very different from the roles consumers and providers normally play out.

b   Processes of participation may be more time consuming than current approaches. This may cause lapses in commitment to participation, especially where staff and other resource are limited.

c   Medical, legal and business jargon used by providers may be incomprehensible and alienating to consumers. This makes it extremely difficult for consumers to break into meeting discussion with their own contribution.

d   Consumers may have limited access to resources for establishment of self-help alternatives and collaborative groups. Limited finances make it difficult for consumers to attend meetings and conferences, where they are not paid to attend.

2 How can a Mental Health Service Facilitate Effective Consumer Participation?

2.1 Meeting consumers' participation needs

The New Zealand National Mental Health consortium of 1989 identified six major needs of consumers which, if fulfilled, allow for effective participation.

1   Validation – consumers need respect from providers and to be given credibility.

2   Power sharing – consumers want to be involved at the decision making level.

3   Information – consumers must be fully informed, for example about their rights and the services that are available to them.

4   Participation skills – consumers need certain skills before they are able to participate as equals. Training opportunities would in some cases be appropriate. Examples of skills required are meeting skills and assertiveness skills.

5   Advocacy – consumers should have the final say in the question of who is to act as their representative.

6   Funding – the establishment of consumer groups requires funds.

2.2 When is consumer participation appropriate?

Consumer participation includes consultation with consumers and inclusion of consumers as members of working parties, and participants at regular meetings of service staff. Consumer participation is appropriate in the following areas.

Staff interviewing and selection	Rehabilitation services
Policy and procedure development	Residential service assessment
Changes to the consumers' development	Quality assurance and system review
Consumer advocacy issues	Mental health promotion and education
Job description development	Educating providers
Planning and needs assessment	Educating the community
Research projects	Mäori and cultural programmes
Purchasing/funding allocation decisions	Development of consumer surveys
Decision making in all the above areas.	

This list is not exhaustive and other opportunities that may arise for consumer involvement can be included. In addition, consumers need the opportunity to express themselves and consult as a group *without* staff input.

Mäori models of advocacy and procedure can benefit all areas of mental health work.. Mäori consumers can be instrumental in ensuring that Mäori consumer issues are addressed throughout the mental health service, including staff interviews, selection and promotion, ward changes, policy and procedure development, and needs assessments.

Other cultures such as Pacific Island cultures also have their own support communities, protocols, customs and mental health concepts. These cultures can also identify their issues in relation to the mental health services.

2.3 Strategies for overcoming the barriers to participation

2.3.1 When initiating participation

a **Making contact with consumers.**

- Discover what consumer groups are in operation locally. Keep a file of such organisations, noting numbers of consumers involved and names of facilitators. Establish networks with current consumers, past consumers/survivors, social services, staff and groups such as GROW and Aotearoa Network of Psychiatric Survivors (ANOPS) locally or nationally for potential consumer participants.

- Be aware that some information and advice may be unavailable locally. Approach consumer groups at a national level where this is appropriate.

- Approach consumer groups and networks in an appropriate way when requesting participation, encouraging trust in the service staff and in the process being followed. Ask them to identify a consumer representative of their choice. Face-to-face contact is appropriate when asking a consumer to become involved in a working group for the first time. Be persistent in requesting involvement in the face of apparent reticence from individual consumers. Continued contact and follow-up with consumers will encourage good links between the service and consumer groups.

- If you are unable to work through a consumer group, check that the potential consumer representatives are in fact representative of the consumers of the service involved. Take care to not use the same consumer representative over and over again – this is likely to promote 'burnout' and also to facilitate the consumer becoming a representative of the service structure rather than an independent advisor. Some consumers choose to work as employees of the service structure and find this a rewarding role.

b **Creating an appropriate environment for consultation**

- Encourage all staff to value consumer input and to recognise its importance. Consumers' expertise is valuable. It is the personal experience which consumers have gained, sometimes over many years and with particular insight, which should be acknowledged by staff; this is a resource which should be put to good use by mental health services through encouraging participation. Mäori input and Mäori consumer input should likewise be valued appropriately. Showing respect and tenacity in approaching consumers for their participation will lead to greater trust from consumers.

- Information regarding the service and individual rights should be accessible to consumers. Such knowledge will increase the likelihood that they can participate on equal terms.

- Encourage staff to make their consumers aware of the consumer advocate and the service he or she provides. Include the advocate in policy or procedure development where possible. This should not take the place of actual consumer consultation.

- The specific goals, objectives and roles to be adopted by all concerned parties should be clarified before the partnership begins. In this way, all parties can make an informed decision about whether they wish to take part. It will also benefit the relationship between the parties by encouraging mutual respect. When planning a consultative process, approach consumers and consumer groups as you would other organisations. You are buying a service from the group, and contracting will take the shape of other contractual processes you are involved in.

- People are more likely to respond if they are invited to participate **before** crucial decisions have been made. In this way, participants have a feeling of ownership, rather than a sense that they are merely responding to another group's agenda.

2.3.2 Structural changes

- Change the culture of the organisation to reflect a consumer world view. Allocate time and resources to changing the ideologies about mental health. Educate staff and consumers and the public.

- A real commitment to participation will be reflected by services building consumer involvement into the existing structures of their organisation.

- Ideally, funding should be provided to allow consumer group members to train in meeting procedure and process. The provision of other resources for consumer groups, such as meeting spaces, is also valuable.

- Funding for individual consumers and consumer groups is important. It may be useful to allocate a budget specifically for funding consumer participation. Make an hourly rate or meeting fee available to all members of a working group who are not being paid to attend. Such payment demonstrates acceptance of and respect for the skills, knowledge and experience of all members. Valuing consumers' experience and expertise can be demonstrated through appropriate remuneration, courtesy during consultation and meeting procedures, and respect for the authenticity of consumer perspectives. Recognise that consumer organisations are involved in other activities such as advocacy in other areas (for example, housing, employment).

- When appointing new staff it is appropriate to look at attitudes towards consumers in the interviewing and appointment process. Employ consumers to be involved in the interview of new staff. All staff should be encouraged to acknowledge the skills and expertise of Mäori and non-Mäori consumers. Staff training by consumers about consumer concerns is important. Treaty of Waitangi training and discussion should also be part of ongoing staff education.

2.3.3 Procedural changes

a **Outside the meeting room**

- Mutually acceptable timetables, agendas and venues should be negotiated. Ensure that the venue is not too formal or overpowering for people who are not accustomed to meetings or boardroom formality. Meeting organisers should take care to provide involved consumers with all meeting dates, information, feedback/minutes and follow up as early as possible.

- Provide consumers with information regarding their rights, available services and how they can influence them. For example, the Ministry of Health pamphlet, *District Inspectors and Official Visitors – How they can help you*, should be available to all consumers.

- Providers should develop and be able to use skills in alternative meeting procedures and alternative decision-making strategies.

- Where possible, provide funding for consumers' transport to meetings (or taxi chits) prior to the event. Use reimbursement after the event only as a last option, as many consumers have extremely limited budgets. Offer assistance to consumers when the meeting arrangements are made.

- Be clear about options to be taken up when a consumer representative or other participant is unable to attend for health or other reasons.

- Talk to consumer groups on a regular basis. No one consumer can represent all.

- Sometimes meetings to which a consumer has been invited will need to address items of a highly technical nature, for example, biochemical interactions of certain drugs, or financial strategies. Consumers' views should be sought before or during the meeting so that the consumer can decide whether they wish to withdraw from such parts of the discussion, or nominate other consumer participants.

b **Inside the meeting room**

- Efforts should be made to establish both parties as equals. Consumers may be reluctant to place themselves in positions where they are dominated by experts. Extra attention to careful facilitation is recommended to ensure consumers are heard.

- Consumers sometimes require social support when participating in mental health service planning, as their involvement carries with it many risks, and they may feel anxious and alienated. Providers should minimise their use of jargon, and explain any complex terms they use. They should also avoid using language which implies that consumers are passive participants or that invalidates them. Be aware also that for some consumers, meeting procedure will be totally foreign. Explanations of procedures and courtesies such as introductions of group members are always helpful. Check with consumers beforehand as to their preferred title – most would not like to be introduced as Ms Doe, Patient.

- Consumers involved in partnership strategies need to pay particular attention to their own mental health needs, as do all workers involved. Sometimes those consumers who agree to participate in mental health planning have many demands placed on them, and participants should be wary of burnout.

- It is appropriate for consumers to act assertively as they work alongside providers and to work as professionals. It is important that health workers provide a safe and supportive environment so that this can happen. The bottom line is that consumer and non-consumer staff alike need to be responsible for their own courteous, professional interactions with other consumer and non-consumer staff.

- Special needs of all members should be considered, and met where possible. For example, a consumer may wish to bring a support person. Allow for regular 'tea breaks' so that everyone who needs to has an opportunity to take a brief pause during the meeting.

- Provide food at meetings when possible as a courtesy to consumers involved. Allow for consumers to bring whänau support where possible and requested. If Mäori consumers are present, include a formal welcome and farewell in the meeting which acknowledges Mäori consumers and other participants respectfully.

- Where possible, invite more than one consumer to attend a meeting. This will give consumer representatives more confidence to attend, and will assist in creating a safe environment for consumers to speak.

- In job interview panels, consumer representatives may wish to ask candidates to show evidence of their commitment to consumer empowerment, and other appropriate questions.

2.4.4 Strategies for evaluation

a **Evaluating the service**

- Evaluation studies should have demonstrable relevance to consumers.

- Consumers should be involved in delineating the outcomes to be assessed when evaluating the service, and also in delineating the way these outcomes are measured. Research indicates that consumers and providers often value different outcomes as measures of success.

- Organise staff education forums where consumers talk about their experiences and concerns, and discussions result, with the opportunity to share ideas, challenge attitudes and values. It may be appropriate to hold ongoing sessions for the benefit of staff, including if necessary a periodic review and redefining of the approach and focus. An independent facilitator could be useful at such sessions to lead discussion and assist in dealing with conflict.

b **Evaluating the participation process**

- It is important that consumers participating in evaluating a service know that their future entitlement to that service is not conditional on taking part, nor threatened by them taking part.

- Make a commitment to review the process of consumer participation in your service regularly. Review of participation processes by consumers and staff will guard against

tokenistic involvement and will encourage proactive and effective liaison with consumers in the future.

Appendix One:
List of Contact Addresses of Consumer Organisations

ANOPS
(Aotearoa Network of Psychiatric Survivors)
PO Box 68-305
Herne Bay
AUCKLAND
Ph (09) 378 7477 Fax (09) 360 2180

Dimensions
PO Box 46-018
Newton
AUCKLAND
Ph (09) 376 2688 Fax (09) 376 0462

Psychiatric Survivors
PO Box 78-172
Grey Lynn
AUCKLAND
Ph (09) 376 0041

Waitakere Interlink
5 Ratanui Street
Henderson
AUCKLAND
Ph (09) 836 1861

Manic Depressive Support Group
C/- Natalie Horlor
28A Walsh Street
HAMILTON
Ph (07) 849 1641

Psychiatric Survivors
C/- Greg Daniels
15A Thames Street
HAMILTON

GROW Group
Pirongia Road
RD 3
OTOROHANGA
Ph (07) 873 6501

Oranga Pai
111 18th Avenue
TAURANGA
Ph (07) 578 4939 Fax (07) 360 2180

Bridges – Fred Zombos
Pupuke Centre, North Shore Hospital
Shakespeare Road
Takapuna
AUCKLAND
Ph (09) 486 1491 ext 2900 Fax (09) 488 0868

GROW National Office
PO Box 8720
Symonds Street
AUCKLAND
Ph (09) 846 6869

Waiheke Psychiatric Support Group
13 Moa Avenue
Oneroa
Waiheke Island
AUCKLAND
Ph (09) 372 8273

Centre 401
PO Box 1183
HAMILTON
Ph (07) 838 0199

Patients Rights Advocacy
65 Tawa Road
HAMILTON
Ph (07) 843 5837

Tenants Group
C/- PO Box 307
HAMILTON
Ph (07) 839 1569

Stepping Out, Whitianga
C/- Mercury Bay House Buffalo
Whitianga
COROMANDEL

Pou Kaha Support Centre – Tony Butler
C/- Community Mental Health
Pyne Street
WHAKATANE
Ph (07) 307 1179/308 4545

Opotiki Mental Health Support Centre
PO Box 591
Opotiki
BAY OF PLENTY
Ph (07) 315 5629

BEAMS
C/- PO Box 2078
ROTORUA
Ph (07) 347 6091 Fax (07) 348 2767

Contact Rotorua
8 Murray Road
ROTORUA
Ph (07) 347 2940

Manic Depressive Support Group
76 Virginia Road
WANGANUI
Ph (06) 345 2264

Wanganui Mental Health Consumers Union
C/- DPA
PO Box 102
WANGANUI
Ph (06) 347 1176 Fax (06) 347 6623

Masterton Consumer Group
C/- Trevor Ward
120 Cockburn Street
MASTERTON
Ph (06) 377 0611

Kapiti Psychiatric Survivors – Rex Thorley
C/- 202A Matai Road
Raumati
KAPITI COAST
Ph (04) 298 4616

Wellington Mental Health Consumers Union
PO Box 11-706
WELLINGTON
Ph (04) 801 7769

Nikau House
335 Trafalgar Square
NELSON
Ph (03) 546 3199 Fax (03) 546 1405

GROW – Cyn Tanner
PO Box 845
CHRISTCHURCH
Ph (03) 366 5890

Matipo Social Club
Unit 1
6 Manette Street
CHRISTCHURCH

Psychiatric Consumer Support and Advisory
Group
York House
67 Worcester Street
CHRISTCHURCH
PH (03) 366 8288

Psychiatric Survivors Trust
10 Sorensons Place
CHRISTCHURCH
Ph (03) 389 3556

The Manic Depressive Society
PO Box 25-068
CHRISTCHURCH
Ph (03) 358 3442

Survivors Fellowship
23 Romilly Street
WESTPORT
Ph (03) 789-8106

Otago MD Support Group – Gary Harvey
4th Floor
14 Princes Street
DUNEDIN
Ph (03) 477 2598

Patients Aid Community Trust
PO Box 1131
DUNEDIN
Ph (03) 477 7638/477 7364

Murray JC Amos
34 William Street
INVERCARGILL
Ph (03) 218 3488

Note: If you are unable to locate a consumer for your area from the list above, contact Aotearoa Network of Psychiatric Survivors in Auckland (address and other details at the top of the list). They hold an up-to-date list of consumer contacts for the whole of New Zealand.

Appendix Two:
Literature Review – Effective Relationships with Consumers

Borus JF, Klerman GC. 1976. Consumer–professional collaboration for evaluation in neighbourhood mental health programmes. *Hospital and Community Psychiatry* 27(6): 401–4.

> Effective service evaluation requires that consumers be involved both in delineating the way the programme is measured and in the evaluation itself. For this to occur, consumers must be able to overcome their distrust of professionals. It is important that consumers do not feel that their future entitlement to services is conditional upon them taking part in the evaluation. Consumers should also feel that their contribution will have a positive impact upon their experiences.

Brotherton P. 1988. Putting consumers first. *The Health Service Journal*, July, 799.

> Brotherton discusses a number of steps that can be taken to empower residents of hospitals. These may also have a wider implication for enhancing consumer participation in a range of services' development. Providers should:
>
> - ensure that they do not use language that implies that consumers are passive or that invalidates them
> - provide consumers with more information about their rights, available services and how they influence them
> - talk to consumer groups – no one consumer can represent all
> - encourage consumers to take a decisive role in working groups [this should be accompanied where needed by training]
> - avoid tokenism, where one consumer is present on a board of 'experts'.

Carling PJ. 1993. Housing and supports for persons with mental illness: emerging approaches to research and practice. *Hospital and Community Psychiatry* 44(5): 439–49.

> Mental health providers and consumers often disagree in assessing the consumer's needs. This is especially true in the case of residential housing. Whilst providers may emphasise treatment outcomes, consumers typically value independence, privacy, safety and productivity over other outcomes. The traditional emphasis on the providers acting 'in the client's best interest' is challenged. Consumers want to be able to choose their living situations and have decisive input into lifestyle choices. Many organisational and attitudinal barriers will need to be overcome before this will happen.

Caro FG. 1981. Reaction of a sceptical sociologist. *Community Mental Health Journal* 17(1): 77–82.

> There are practical difficulties in terms of effective consumer participation in decision making and evaluation of social services. Programmes are frequently complex, and require not only time and commitment, but also knowledge and skills regarding procedural frameworks, bureaucratic processes etc. Training therefore is an important issue. This also has relevance to evaluation. Often professionals develop the methodology and define the issues that need to be addressed. Caro argues that it is useful for consumers to engage in their own evaluations, identifying those issues central to them.

Church K. 1989. User involvement in the mental health field in Canada. *Canada's Mental Health* 22–5.

> Three categories of user involvement are described: consumer control, coalitions/ partnerships and consumer participation. The author focuses on power. An important barrier to participation is the difficulty in restoring consumers' power within a disempowering system. It is important to create the conditions whereby people can reclaim power on their own terms. Financial costs are also a major issue.

Dinkel NR, Zinober JW, Flaherty EW. 1981. Citizen participation in CMHC programme evaluation: a neglected potential. *Community Mental Health Journal* 17(1): 54–65.

> The roles consumers may play in evaluation range from activities such as the passive receipt of information through to actively conducting studies. The latter is necessary if such endeavours are not to be seen as tokenistic.

> Suggestions are made to counter the barriers to participation, both at the policy level and the local level, including:
> - a definition prior to evaluating the specific goals of consumer involvement
> - a definition of what is meant by representative consumers should be developed (for example, the consumer constituencies include past and present recipients of services, distinct ethnic and demographic groups etc)
> - technical assistance and training to consumers should be provided
> - a fixed budget should be made available to the consumer group.

Everett B, Steven LD. 1989. Working together: A consumer participation research project to develop a new model of high-support housing. *Canada's Mental Health* 28–32.

> The study examined the process of consumer participation in mental health research. A number of strategies were employed to reduce the traditional barriers between professionals and consumers. The first stage was to inform consumers of the aims of the study and their role, so that they could give (or not) informed consent to their participation. Communication was also viewed as important to ensure that the consumer committee never felt alienated. At the completion of data gathering, consumers had an equal role in interpreting results. Informal gatherings were seen as useful, as they helped break down interpersonal barriers and thus enhanced participants' ability to contribute in the more formalised meetings. These principles may also be applied to other participatory endeavours within the area of mental health.

Kopolow LE. 1981. Client participation in mental health service delivery. *Community Mental Health Journal* 17(1): 46–53.

> *'Increased client input could lead to more responsive services, diminished cost of centre operation, improved outreach and the development of more collaborative and less paternalistic treatment regimes'* (p 52).

> Suggestions are made to overcome the problems inherent in enhancing collaboration between consumer groups and mental health providers.
> - Efforts must be made to establish both parties as equal. Consumers may hesitate to place themselves in a position where they may be dominated by experts.
> - There must be consumer representation on advisory and governing boards.

- Funding is important, so that limited finances do not, for example, prevent consumers from attending meetings or having input into conferences.

Lord J. 1989. The potential of consumer participation: sources of understanding. *Canada's Mental Health* 15–17.

Consumer participation in mental health can exist on three levels: the individual treatment level, consumers in agencies/organisations providing services, and at a planning and policy decision making level.

Participation involves listening to consumers with respect to their different perspectives. This is most salient in the area of needs assessment. Research has demonstrated that providers and consumers may highlight different issues as being important in service provision.

Partnership models may be effective mechanisms for change. Lord cautions that for such models to be effective, providers must modify their roles in order to minimise the 'professional distance' between themselves and consumers. Strong facilitators are needed to maintain equality between the collaborating parties.

Developing self-help organisations is another important way in which consumers can participate in the mental health field.

McIver S. 1991. *Obtaining the Views of Users of Mental Health Services.* London: King's Fund Centre.

This publication is aimed at helping health service staff to obtain the views of mental health service users. It is easy to read and provides sample question and response formats which can be adapted. Information about survey and non-survey methods is provided.

Mowbray CT, Chamberlain P, Jennings M, et al. 1988. Consumer run mental health services: results from five demonstration projects. *Community Mental Health Journal* 24(2): 151–6.

Five consumer-run mental health services were briefly described. Overall results suggested that these projects were successful in terms of enhancing social interaction, communication and promoting skill development. Cost for the services were low, but this was due to the extensive reliance on volunteers. Authors caution that those heavily involved in providing services, for example in advocacy and support, need to be aware of looking after their own mental health needs. Training was valuable, but volunteers also needed some support themselves. A high volunteer turnover demonstrated the stresses involved in providing assistance.

National Mental Health Consortium. 1989. *The Consumer Report.* Wellington: Department of Health and Department of Social Welfare.

One of the stated policy objectives of the consortium was to empower consumers and consumer groups to participate in service planning, delivery and evaluation.

"*Matching the service to the consumer rather than vice versa should be one central aim of community care*" (p 3).

To fully participate, consumer groups need:
- validation: that is, respect paid to them by providers
- power sharing: consultation and advice given is regarded as tokenistic
- information regarding rights, access to services etc

- advocacy: consumers should direct who is to represent them
- funding.

Participation may be either in the form of partnership with providers, or in establishing independent self-help alternatives.

O'Hagan M. 1991. *Stopovers on My Way Home from Mars: A Winston Churchill Fellowship Report on the Psychiatric Survivor Movement in the USA, Britain and the Netherlands.* Auckland: Winston Churchill Fellowship.

O'Hagan writes that 'being the sole representative of a disempowered group in a powerful organisation can be a lonely and disempowering experience' (p 48). A way to counter this, while maintaining participation, is to second survivors from consumer organisations. In this way, their position is validated and they have the support from an organisation of peers, while networking and providing input into policy.

Prestsby JE, Wandersman A, Florin P, et al. 1990. Benefits, costs, incentive management and participation in voluntary organisations: a means to understanding and promoting empowerment. *American Journal of Community Psychology* 18(1): 117–49.

> *'Social exchange and political economy theories are applied to the examination of voluntary organisation participation and viability to understand individual and organisational empowerment ... individual participation is facilitated by participatory benefits [and] hindered by participatory costs'* (pp 117–18).

A strategy for increasing individual participation is for the organisation to manage the incentives provided for participation and decrease the costs involved. Incentives may be material, social/communal or purposive (eg, bettering the community).

The results of the study have implications for the promotion of participation.
- Community organisations should strive to increase the benefits and decrease the costs associated with participation.
- Incentive and cost management efforts should be tailored to the targeted group. A needs assessment may be helpful to determine the desired benefits and experienced costs.
- Both selective incentives (of benefits to the individual, that is, skill training) and communal incentives (that is, the products of participation with wider ramifications) are important.

Although this model has been applied to voluntary organisations, such analyses have implications for broader participatory activities.

Todres R. 1989. The self-help clearinghouse of metropolitan Toronto: an innovative approach to consumer participation. *Canada's Mental Health* 26–7.

Todres discusses the function of a 'self-help clearinghouse' in Toronto. Its purpose is to inform and educate the general community and the professional helping community about self-help groups, to provide appropriate assistance to existing self-help groups to meet their own organisation objectives, to obtain maximum participation from the self-help movement in its development and operation, and to start new self-help groups.

The clearinghouse model is advocated as a useful way to strengthen and broaden the range of self-help programmes available in the mental health sector, and thus enhance consumer participation.

Valentine MB, Capponi P. 1989. Mental health consumer participation on boards and committees: barriers and strategies. *Canada's Mental Health* 8–12.

> *'The article provides an overview of factors related to the participation of consumers of mental health services on boards and committees. Six primary barriers to effective consumer participation are addressed: incongruence between stated values and actual practice, tokenism, lack of representativeness, role strain, poor communication and economic factors"* (p 8).

A number of strategies are proposed to enhance effective consumer participation, including the follows:

- Make practices consistent with values. If consumer participation is valued, then the degree and style of participation should reflect this.
- Eliminate tokenism: steps should be taken to avoid under-utilisation/under-representation of consumers. Consensus in the literature suggests that 25–50% of a board's composition should consist of consumers.
- Seek representativeness, not just representation.
- Educate members to minimise role strain. Orientation training should be undertaken by all board members. Specifics related to consumer and professional role strain should be addressed.
- Improve communication. Jargon should be avoided. All members must be given a chance to air their views. Informal interaction may also be valuable. Consideration of the special needs of members should be made. For example, if medication makes a member's vision blurred, memos in larger fonts may be appropriate.
- Make participation economically feasible.

Walch H. 1991. *A Challenge to Service Providers – Changes to the Relationship between Mental Health Providers and Consumers: A Report to the Winston Churchill Trust.* Wellington: Inner City Mission.

Walch offers a number of guidelines to mental health providers to facilitate a more equitable partnership between themselves and consumers in service provision.

- Recognise that there is often a great deal of commonality between consumers' and providers' aspirations, but inequity of opportunities to fulfil these goals.
- Identify before approaching the consumer/consumer group what the proposed relationship will be, so that consumers are in a position to decide whether to become involved.
- Remember that both groups may lack skills to work together, and thus both will need to be flexible in the principle of partnership.
- Negotiate mutually acceptable meetings, venues and agendas.
- Avoid jargon and meeting practices that may alienate either party.
- Adequate resources, training and information need to be available to consumers so they can actively engage in dialogue with providers.
- Service providers may need training in skills such as consensus decision making.

- Neither group should 'manage' the course of events.

White JCM. 1989. Consumer participation: a personal journey. *Canada's Mental Health* 2–4.

White offers a personal account of her experiences as a consumer participating in mental health planning. The risks consumers take in participating are highlighted:

> *'We speak in the first person, not the academic third person. We give ourselves along with our knowledge'* (p 4).

Consumer participation therefore requires not only economic support, but social support. Social support includes listening, accepting differences, recognising that consumers may feel anxious and alienated, recognising their value and working together to change attitudes and systems.

Windle C, Cibulka JG. 1981. A framework for understanding participation in community mental health services. *Community Mental Health Journal* 17(1): 4–18.

Windle and Cibulka offer a three-dimensional matrix by which citizen participation in community mental health services can be understood. The power continuum has three elements: whether citizens have power in terms of delegating authority figures, controlling groups themselves or in partnership with mental health providers; whether this power is tokenistic; and whether citizens do not have power (for example in some therapy situations). The functional dimension is analysed in terms of how this power is manifested in service development; that is in authorising the programme, providing resources, planning, governing, service provision and programme evaluation. Finally, the participant dimension examines which citizens are involved in the programme; the community, employees or consumers themselves. Each dimension is important when attempting to assess the level of actual participation by consumers in mental health services. They provide a useful framework by which other studies can be understood.

Windle C, Paschall NC. 1981. Client participation in CMHC programme evaluation: increasing incidence, inadequate involvement. *Community Mental Health Journal* 17(1): 66–76.

Client satisfaction surveys and client complaint systems are two forms of service evaluation that have the potential to involve consumer participation. To date such efforts have been largely tokenistic as measures have been primarily developed by technicians without consumer involvement, and frequently haven't addressed issues that consumers value. Bias may occur when assessments are administered by the agency. Involvement of clients as both the designers and the administrators of such measures improves the validity of such evaluative tools.

Woodside H. 1990. National perspective. *Canadian Journal of Occupational Therapy* 58(1): 3–5.

Consumers participating in mental health delivery must believe that their contributions will be of value, and experience benefits and rewards from that participation. However:

> *'most of those with chronic mental illness have a long history of institutionalisation and/or being cared for by someone. They have been socialised to be passive, their day-to-day experiences are narrow, they have rarely been in a position of power, and their credibility is questioned'* (p 4).

If consumers can learn effective decision-making techniques and gain confidence in them, learn the roles that they will be expected to take for participation, and learn the skills required to facilitate this, then consumers will be better placed to participate.

Appendix Three:
Assessing Consumer Participation in Mental Health Settings

Centre for Community Change through Housing and Support
Trinity College
Burlington, Vermont, USA

The following questions ask about the degree of consumer involvement in your agency activities. These questions can be used to help identify areas in which to increase consumer participation. This is not an exhaustive list; expand it collaboratively with agency consumers and staff.

1 **Policy**

    a   Does your agency have an explicit policy on consumer participation in planning, decision making, and service provision?

    b   Is this a written policy?

    c   Is this policy widely promulgated (eg, would all staff and consumers be aware of it)?

2 **The Agency Board**

    a   How many consumers are board members? What percentage of all board members is this?

    b   Are these consumer board members voting members?

    c   How many consumers participate in board committees and advisory groups?

    d   How do you recruit new consumers to participate in your board?

    e   What reasonable accommodations for board participation are in place (eg, orientation, training, transportation, other supports)?

3 **Consumer employment**

    a   Does your EEO policy explicitly state a non-discrimination clause for people with psychiatric histories? Does your EEO policy explicitly state a preference clause for people with psychiatric histories?

    b   Do you hire staff who have psychiatric histories?

    c   When recruiting for new staff, do you advertise in a way that attracts consumers?

    d   Do you have reasonable accommodation policies and practices to support employment?

    e   Do you provide training to staff on the kinds of reasonable accommodations that people with psychiatric disabilities may need?

    f   Are consumer staff afforded the same roles and access to information as are non-consumer staff?

4   **Agency services**

a   Does the agency regularly solicit consumer input into service planning and service provision? Is this input used to alter service provision practices?

b   Are the services which you offer based, even in part, on the stated needs and preferences of your customers?

c   Are consumers involved in evaluating agency services? Do you routinely conduct consumer satisfaction studies?

d   Are consumers involved in hiring decisions?

e   Do you have specific mechanisms in place through which consumers can report and resolve grievances, review their treatment records, and review treatment decisions? Would staff and consumers know about these mechanisms?

5   **Agency training and special events**

a   Are consumers invited to participate in agency training events?

b   Do consumers act as trainers at agency training events?

c   Do consumers participate in training and orienting new staff?

d   Do you sponsor event/forums that educate consumers about their rights and entitlements?

e   Does the agency co-sponsor events with local consumer groups?