

Consumer participation in mental health services: who wants it and why?

MARGARET TOBIN, LUXIN CHEN AND COLLEEN LEATHLEY

Margaret Tobin is currently State Director of Mental Health Services, SA and Associate Clinical Professor at the Adelaide University. She was formerly the Area Director of Mental Health, South East Health at the time of the study.

Luxin Chen was Manager, Service Evaluation and Research, Area Mental Health Services, South East Health at the time of the study.

Ms Colleen Leathley was Project Officer, Consumer Participation Project, Area Mental Health Services, South East Health at the time of the study.

Abstract

Contemporary health policy dictates that health services have a demonstrable consumer focus and actively progress the issue of consumer participation in services. Given that costs of such initiatives are not insignificant, there is a responsibility to ensure that the resources are being directed to appropriate means, and are achieving worthwhile results.

In examining the impact and effectiveness of consumer participation initiatives in their own Service, the authors undertook a qualitative study exploring the extent and quality of consumer participation following a three-year period of support and funding. Using trained consumers as interviewers, current consumers were asked about their perceptions and personal experience of "participation".

Findings identified low familiarity and involvement with the concept of consumer participation overall. Barriers to involvement included lack of motivation or invitation, stigma, and a lack of information. A need to integrate consumer participation activities into the wider system was also noted.

The authors conclude that simply devoting energy and resources to consumer initiatives, and thereby achieving a politically correct approach, may not be a worthwhile exercise. Such initiatives need to be based on evidence, available resources and identifiable and achievable outcomes, with a balance struck between endorsing the value of consumer participation and establishing realistic goals for what can be offered and managed.

Introduction: consumer issues in Mental Health Services

The issue of consumer participation in mental health services has become important internationally. In Australia, it has been articulated in the National Mental Health Strategy (Australian Health Ministers 1992), and the Second National Mental Health Plan (Australian Health Ministers 1998). This direction has been translated into policy at the State level (NSW Health Department 1998).

Local responses to national strategy

In response to these national and state directions, local service providers have undertaken a number of initiatives. For example, the mental health program run by South East Health, a metropolitan health region in Sydney, Australia, has facilitated the development of local consumer networks, employed a full-time Consumer Coordinator, and instigated consumer consultative committees at each service provision site. Consumers have been recruited and paid to participate in a variety of planning, service development and quality improvement committees.

Some service providers have questioned the value of introducing such initiatives, requesting evidence that they are an effective means of encouraging broader consumer participation or have a positive impact on the health of individuals or groups. At present, such evidence is not available. In the midst of the rhetoric of political correctness, discussion of the objectives, challenges, and priorities for consumer participation initiatives has been limited. Even if we take as a fundamental value in itself that consumer participation as something good, this does not allow us to assume that all initiatives in this direction are unequivocally able to deliver this outcome.

Thus we considered it timely to review what has been achieved, and whether there are demonstrable levels of consumer participation within our mental health services. We were interested in canvassing mental health consumers' views and experiences of participation, and determining what may be some of the future challenges. The study described in this paper, undertaken in collaboration with a group of consumers, explores these issues.

Who is a consumer?

The term consumer is one in a long list of labels that users of mental health services have applied to themselves. Such terms include client, consumer, customer, patient, ex-patient, and psychiatric survivor (Lord 1989).

Historically, the term 'consumer' was derived from a commercial base and referred to the relationship between service providers and purchasers. Within this framework, keeping consumers satisfied is a primary goal because it leads to increased consumption, and hence more profit. In the publicly funded health sector, however, services are planned, funded and delivered to meet needs within finite resources and increased 'business' is not always desirable. In such a setting, consumer choice is limited.

Nevertheless, consumers have been influential in shaping health systems in several ways. Changes that have occurred from traditional service provision models are evident in diabetes, HIV, breastfeeding and birthing practices. Each has had a specific focus, and been driven to meet specific needs and issues of consumers. Mental health consumers have been influential in the establishment of model day programs such as "Clubhouse" (Farrell & Deeds 1997), but have had less impact on treatment services.

Understanding current concepts in consumer participation

Lord (1989) identified three different levels of consumer participation. The first is the individual treatment or service level, which involves discussion and engagement with a service provider. The second is at the agency or organisational level, which involves participation on boards or committees. The third is the active involvement of consumers in community, regional, and national planning and policy decision-making. Similar levels have been identified by Church (1989).

Arnstein (1969) proposed a ladder of participation, in which consumers progress through 8 stages from being passive recipients, to token players, to having full citizen power and being actively engaged in planning and policy. The model appears elegant in form, but it has not been validated in practice.

Lynch (1997) observed that the goals of involving the consumer are usually to improve health outcomes, increase satisfaction, reduce cost, or a combination of these factors. He identified two distinguishing features of consumer-focused activities as follows:

- 1 the activity involves some change in the consumer's knowledge or skill about participation in the health system
- 2 the presumed outcomes stem from an underlying premise that it is the individual's involvement, as a decision-maker or self-manager, that will produce positive outcomes.

Consumer participation in mental health in Australia

In recent years, mental health systems of care in Australia have undergone a great deal of change. Parliamentary reviews and public enquiries into aspects of facilities and systems [for example, the National Inquiry into Human Rights and Mental Illness (Burdekin et al 1993)] have resulted in a move towards a more consumer-focused delivery.

What this increase in consumer focus and sensitivity has achieved in real terms has not been systematically evaluated. The critical question remains: what are the demonstrable outcomes of the political rhetoric supporting consumer participation?

Patient-clinician communication as an aspect of consumer participation

One aspect of consumer participation that has received some research attention is that of the individual treatment level. The patient-clinician relationship has been identified as being a key factor in how consumers feel and respond about treatment (Ong et al 1995).

This perspective suggests that the opportunities for consumer participation occur first at this clinical interface in terms of what information is transferred, in what direction, and in how the communication takes place. Nurturing participation at this level has a fundamental role in consumer empowerment.

Much discussion of patient-clinician communication is based on power and/or information asymmetry between the two, and on their differences in values and preferences. Two normative models of treatment decision making (Gafni et al 1998) are widely accepted in the research field. In the first, the clinician is a “perfect agent” for his/her patients, and they delegate authority to their doctor to make treatment decisions, based on his/her determination of their preference. The second model is the “informed decision making model”, where the patient takes full responsibility for making the treatment decision, based on information transfer from the clinician.

The same group of researchers identified a middle choice called “shared decision-making” (Gafni & Whelan 1997). Empirical research demonstrates that many patients prefer not to assume full decision-making control, but neither do they like the idea of having no say at all. The challenge in adopting this model lies in determining how the shared decision-making should take place. Shared decision making was also the preferred model described by Wyke (1997).

Related aspects of consumer participation

Another aspect of participation that has received research attention is consumer satisfaction. With finite health resources, not all consumer preferences, needs or requests can be met. Priorities have to be determined, and choices made. There is, however, a strong belief that it is a fundamental right of consumers to participate in shaping services that are primarily supposed to be for their benefit. Achieving the appropriate balance is not always comfortable. There is some evidence that designing services which address consumer satisfaction leads to better outcomes (Fisher 1994 & Salzer 1997). However, there is also strong evidence that satisfaction does not necessarily equate with treatment success (El-Guebaly et al 1983), and that the nearly uniform positive results of consumer satisfaction surveys conducted by staff calls into question their utility as a viable outcome measure (Gill et al 1998). Williams (1994) similarly questions whether ‘consumer satisfaction’ surveys constitute an evaluation. Despite this, use of consumer surveys has been widespread and not always resulting in appropriate service responses (Tobin et al 1998).

In a recent more rigorously designed evaluation of consumer participation in a public sector mental health service (Victorian Mental Health Service 1999), it was reported that improved consumer participation had led to significant and positive changes at the level of individual treatment, service design, delivery and evaluation. However, considerable variation was identified between and within regional/district Mental Health services in terms of understanding what consumer participation is, its aims, and the effectiveness of strategies to increase its level. The researchers recommended a number of initiatives including clarification and reinforcement of policy direction, information sharing, adoption and monitoring of protocols and structures, and training and development for both staff and consumers.

Costs associated with consumer participation

Using these Victorian recommendations as a guide, it is clear that there are significant costs associated with ensuring effective and adequate consumer participation.

Quantifying these costs may be difficult, especially if we include the informal and voluntary component of such participation. Within South East Health, the direct costs of employing a consumer co-ordinator, paying consumers for their participation in service development, supporting consumer-based initiatives and other associated costs were estimated in the 1998-99 financial year to be approximately 1% of the \$50m annual expenditure. Indirect service costs are more difficult to quantify. These include staff resources directed to support consumer participation initiatives, time costs for managers and clinicians to be away from other activities, use of premises and equipment, reimbursement of travel expenses for consumers to attend meetings, ensuring participating consumers have access to staff for support, and staff development activities.

In addition, it has been recognised that health initiatives that are reliant on public participation often place an additional burden on already disadvantaged individuals and groups. There are significant costs involved in such participatory activities. These include personal time, expenditure, training costs, and information dissemination costs. All are ongoing and subject to peaks of demand (Lord 1989). Unless these are taken into account, only the more privileged sectors of society can participate, thereby excluding and possibly worsening conditions for citizens from disadvantaged groups.

Increased consumer participation could also have “costs” for clinicians. Coulter (1995) notes that “consumer requirements” may define quality standards and may even evaluate individual clinicians, which in turn may confront personal, social and professional values, such as autonomy, esteem and professionalism, which are important to clinicians. This is a new challenge facing the health professions.

Given this significant commitment of resources, it is entirely appropriate that questions are asked about the effectiveness of any initiatives in actually improving consumer participation and about the added value of achieving improved levels. We argue that consumer participation initiatives should be subject to scrutiny based on what level of participation is achieved, what are the tangible benefits, and what are the costs. The first of these questions was addressed in this study.

The service context

South East Health provides a range of health services to approximately 750,000 residents. The mental health program comprises four integrated inpatient and community mental health teams in four geographic locations. Prior to the study, one of these services had had a 4-year history of investment in participation and advocacy projects. Another had a relatively shorter history of investment in consumer issues with fewer resources, which had been largely directed to the education and training of consumers to participate in committees. These two services were studied in this project.

The aim of the project was to evaluate the level, extent and quality of consumer participation, and to examine whether there were demonstrable differences between services with different resource commitments.

Methodology

The project was managed by a steering committee that comprised the program director, two researchers, a clinician psychiatrist who is an advocate for consumer participation, the full-time salaried Consumer Coordinator, and four consumers nominated by consumer consultative committees. Through a process of discussion, the Steering Committee reached agreement on the methodology and the specific information to be sought.

It broke into subsections the key question of consumer participation including current level of knowledge and interest actual levels of involvement, and perceived needs for greater participation opportunities.

From the outset, the Steering Committee resolved that the research itself would have a consumer participation orientation. Thus the original questionnaire format proposed by the research team was rejected in favour of face-to-face interviews with consumers by consumers. The rationale behind this decision was that consumers would be more likely to describe their views of participation if no staff were present. Use of tape recorders was also rejected for the same reason. Agreement was reached on the use of a semi-structured interview in the interests of simplifying analysis of the results.

A series of questions suggested for the interview was iteratively proposed, discarded, adjusted, simplified and eventually agreed. The questions which were ultimately accepted related to consumers' perceptions of their levels of participation; and how much encouragement they received to participate in their own treatment, in service development activities, and in consumer-initiated projects. These levels roughly equated to Lord's (1989) three categories, although for local relevance, consumer-initiated projects were substituted for national policy involvement. On the advice of consumers, the language of “consumer participation” was supplemented in each question by the phrase, “having a say”.

Identifying the cohort

The consumers from whom opinions were sought were current consumers in contact with any aspect of the service at an identified point in time. We obtained a census of all users of inpatient and outpatient services, day programs, community teams, consumer consultative committees and consumer-led activities, at particular points in time over a 2-week period.

Consumers who were acutely unwell on the day in question (eg, consumers recently admitted to acute locked ward inpatient unit, or consumers requiring acute crisis team intervention) were excluded. All others were approached on the day of attendance by one of the research team, and asked if they would participate in a study looking at consumer participation. Those who agreed to participate were asked to provide a contact telephone number and address and were told they would be contacted by a trained consumer interviewer to arrange an interview.

A cohort of 122 consumers were identified and asked to participate. Of these, 70 (57%) declined, and 52 (43%) agreed. Of the 52 who initially agreed, 16 (31%) withdrew prior to completing the interview, leaving a total of 36 consumers (30% of the original sample) who completed the interviews. Reasons given for non-participation in the project included lack of time, side effects of medication, unstable illness, other commitments, and lack of interest in or knowledge of the area.

An analysis of the full cohort of 122 consumers in terms of socio-demographic and illness profiles was undertaken to determine whether the consumers who agreed to participate differed from the whole group. Comparisons were also made of site and type of service so that inter-service comparisons could be made.

Consumer interviewers were recruited via advertisements placed in strategic locations that consumers were likely to notice, such as noticeboards, local educational institutions, community health centres and inpatient units. A selection panel was established that comprised consumers and the research team. The selection criteria included a history of having been a consumer of mental health services; having an interest in consumer participation issues; and demonstrating ability to undertake interviewing in a semi-structured format.

In their application forms, prospective interviewers were also asked to describe their perspective of consumer participation. These responses were included in the analysis to examine whether there were any differences between their and the interviewees' levels of knowledge and interest.

Of 65 written applications received, 23 were short-listed for interview and 11 were selected. They underwent a paid 2-day training program that was conducted by the Professor of Mental Health Nursing. After training, interviewers were paired to conduct the interviews. One managed the interview using the prepared semi-structured format and the other acted as scribe.

Interviews were conducted in several health service settings in order to maximise convenience for the consumer. Participants were assured that any information disclosed would be treated confidentially, and would only be used for the purpose of determining services' uptake of participation issues. They were also informed of their rights to terminate the interview at any time without effect on their relationship with the service. The style and content of this "participant's rights" information was determined in consultation with the St George Hospital Ethics Committee.

The 36 interviews occurred over the course of 12 weeks. Interviewees were given an introduction to the project, and a brief overview of the issue. They were then asked 4 questions, with written prompts provided to interviewers to supplement each question if inadequate information was forthcoming. The questionnaire is shown in Figure 1.

Figure 1: interview questions

Q1.	Consumer Participation or "Having a Say", have you heard of it and what does it mean to you?
Q2.	Do you feel that you can "have a say", and can participate in planning and making decisions about your own treatment and recovery?
Q3.	Have you ever participated or "had a say" about Mental Health Services in policy development; planning, delivery or evaluation of mental health services; or being on a mental health committee?
Q4.	Have you ever participated or had a say in activities or services that have been consumer driven/run/lead within the South Eastern Sydney Area Health Service?

The detailed notes taken at the interviews were subject to content analysis by the research team and were made available in non-identifiable format to the Steering Committee for additional comment.

Results

Demographic data were compared for those participating and not participating in the interviews. As seen in Figure 2, very few differences were identified. The two groups were similar in terms of age, presence of psychotic illness and average duration of illness. Observed but not significant differences were found between gender (more males participated than females) and Non-English Speaking Background (a greater proportion of consumers from a non-English speaking background declined to participate than did those from an English speaking background).

Figure 2: demographic profile of interviewees

	Consumers participating in interviews [n=36]	Consumers not participating in interviews [n=86]
Age:		
Range	20-89 yrs	17-84 yrs
Average Age	47 yrs	43.5 yrs
Gender:		
Male	23 [64%]	48 [56%]
Female	13 [36%]	38 [44%]
% with psychotic illness	24 [66.7%]	60 [69.8%]
Average duration of illness	5.2 yrs	5.3 yrs
No. with NESB background	5 [17%]	23 [26.7%]

Consumers' knowledge and understanding of consumer participation

A broad range of responses was noted, ranging from no familiarity or understanding of the concept at all, through to a comprehensive understanding and even personal experience. Overall fewer than half of those interviewed were in any way familiar with the concept.

Figure 3: comparison between sites

	Site with history of well-resourced consumer participation [n=20]	Sites with history of less well-resourced participation [n=16]
Familiar with concept of consumer participation	8 [40%]	6 [37.5%]
Not familiar with concept of consumer participation	12 [60%]	10 [62.5%]

Resources committed by services to consumer participation initiatives did not correlate with higher rates of understanding of consumer participation.

Where participation was reported as being a familiar concept, it mainly appeared to reflect being able to discuss treatment options or difficulties with a doctor or case manager; having input into decisions in a group home; or being involved in planning of consumer groups or social outings. One consumer noted a broader perspective of empowerment, describing participation as “getting as many people, consumers, involved in the mental health service and letting them know of their rights”. For another consumer, “awareness of the system and having a say in the system” was important.

Consumers’ participation in making decisions about their own treatment and recovery

There was a range of responses to this question. Fewer than half felt they could or did have a say in their own treatment and recovery, while the remainder deemed such an opportunity to be nil or extremely limited. An important factor seemed to be the degree of rapport between patient and clinician. Those who reported having a “good” general practitioner, psychiatrist or case manager tended to be more able to ‘have a say’ in their treatment and recovery. As one consumer noted “The doctor does not just tell me what to do. I tell her the level of medication, and she is willing to adjust if there is a problem. People don’t realise they can have a say. It’s my body! It is up to the individual, ask to see the doctor more often”.

Others who felt it was not their place to question the doctor were less sure of their ability or desire to ‘have a say’, with one consumer noting “When I go to the doctor, he does doctoring. There is nothing forthcoming from it. Get more pills or no pills”. Another consumer indicated an aspect of learned helplessness, noting that “if treatment wasn’t right I would say something, but it is up to the doctor. I can only suggest. I basically tell them what I want but it ends up going their way”. There was no difference between the two services in this regard.

Levels of involvement in service development activities

One consumer reported being involved in the consultation process when the Mental Health Act was being introduced to Parliament, and another had been involved in helping set up consumer consultative committees and groups. The remainder had no experience at this level.

Expressed barriers to such involvement included lack of opportunity, information, confidence or motivation. Reasons ranged from being too busy to get involved, transport difficulties, hearing difficulties, shyness, lack of exposure to such opportunities, and lack of interest or motivation.

Involvement in consumer-initiated projects

Overall, this was low. Whilst 15 interviewees reported some involvement in ‘consumer-led groups’, on more detailed reflection it was noted that they were generally referring to staff-led programs (such as rehabilitation activities) which had consumer input. Experience with genuine consumer-initiated, led or driven programs was extremely low.

Interviewers’ themes

These responses tended to comprise a broader, more diversified description of consumer participation issues. Applicants spoke of advocacy, shared decision-making, empowerment, lobbying and involvement. There was no difference in the range of responses between those selected to be interviewees and those who were not.

Discussion

Achievement of participation

This study highlighted a number of issues. The overall low level of knowledge and interest in consumer participation poses challenges for service managers who are committed to improving the consumer focus of their programs.

The high decline rate (70% of those approached declined to participate) is also of concern. Reasons for not wanting to participate included an expressed unwillingness to be labelled as a mental health consumer; an

inability to understand the purpose or requirements of the project; suspicion of the project's intent; or a desire to be left alone. Both participants and non-participants were representative of longer-term service users. Thus the generalisability of the findings to a broader group of consumers of mental health services is not known.

Consumers who had interest in and experience of participation described receiving encouragement from family, friends, staff or fellow consumers to be involved. Those not involved reported not being asked or not knowing anything about it. There was no correlation between general levels of consumer interest and involvement in participation, and the recent resources and time commitment of the service to consumer initiatives. This is an important finding because it challenges us to examine our methods for consumer engagement, in terms of their effectiveness.

The correlation between having a good relationship with a clinician and higher levels of participation implicates communication skills development in staff as an important issue. This is consistent with findings by Ong et al. (1995) and the Consumers' Health Forum of Australia (1997). It suggests that efforts focussed mainly on consumer advocacy and training which characterise many of the previous initiatives in our services may be less effective than initiatives designed to improve the skills of our staff in communicating with consumers about their rights.

Unfortunately, the narrow sample of consumers interviewed, the high decline rate, and the relatively low levels of interest and involvement in consumer participation mean that caution must be taken in extrapolating from these results. The study has provided some useful insights, but it has raised more questions, for example: How do we actually determine what consumers think about participation when only small numbers may wish to participate in discussion? Is this finding indicative of all health settings, or mental health in particular? Are most consumers generally more interested in their own treatment than in policy and planning of health services? If so, what are the implications for engaging consumers in service development? How do we canvass the views of consumers broadly and reduce the risk of sectional interests of consumers being the only contributors to the debate?

Implications for mental health services

Whilst accepting the value of enhancing consumer participation, achieving significant uptake will require systematic responses. Simply directing energy and resources to consumer initiatives, without ensuring that they are complemented by initiatives engaging clinicians, appears unwise. It is essential that resources directed to enhancing consumer participation be evaluated for effectiveness. In doing so, a balance needs to be achieved between endorsing the value of consumer participation and establishing realistic objectives for what can be offered and managed.

In this Area, in collaboration with consumers, we have committed to the development and implementation of a broad education strategy. This will include facilitating the development/collation of resources for consumers and carers about their rights, opportunities and avenues for participation, and producing resources for staff aimed at increasing awareness and skills in communicating with consumers about their choices and rights.

Challenges inherent within the methodology

The Steering Committee, comprising as it did researchers, staff and consumers, presented methodological opportunities and difficulties. These are worth noting for their impact on reliability and validity of the results, and for their implications for future research.

Using consumers exclusively as interviewers and scribes demonstrated our commitment to working collaboratively with consumers, and represented a learning opportunity for the researchers and staff involved. It may also have encouraged consumers to be more open and forthcoming with information. Unfortunately, the reliability of the data was compromised by having multiple interviewers, lack of control over interview style, and wide variations in the skills of interviewers. With hindsight, the training and skilling of one or two consumer interviewers and scribes may have produced greater reliability in content.

Conclusion

Recognising the challenges of enhancing consumer participation is one thing; meeting them is another. As providers committed to the concept of consumer participation, we have a responsibility to ensure that effective strategies are used. Given the paucity of evidence to support any current strategies, all initiatives must be evaluated against effectiveness criteria.

Each site and service needs to determine for itself how it best engages consumers in the shaping of service culture. We argue that such decisions must be based on whatever evidence is available and be open to continual searching for new alternatives. Merely endorsing the value of consumer participation is insufficient. We must ensure that it is pursued not just as rhetoric but also in a meaningful way.

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