Consumer and carer participation in mental health services

Chris Lloyd and Robert King

Objective: *To clarify the meaning of consumer and carer participation in mental health services, to identify reasons why consumer participation is important both to consumers and to services, and to discuss barriers to participation and ways of overcoming these barriers.*

Conclusions: *Consumer and carer participation has been promoted as part of the National Mental Health Strategy and has the potential to empower consumers and their carers and to improve mental health services. Barriers to consumer participation include professional staff attitudes and resource allocation. Guidelines are provided to assist services to address these barriers and increase the level of consumer and carer participation in both clinical decision-making and service development.*

Key words: *carer, consumer, mental health services.*

Mental health reform has seen substantial changes in the delivery of services. Initiatives have been directed towards structural reform of mental health services, improving linkages with stakeholders and promotion and prevention.[1] There has been an emphasis on service quality and effectiveness and with enhancing outcomes for consumers. The National Mental Health Strategy has provided the basis for improving consumer and carer participation in decision-making, advocacy and outcome measurement.[1] This has been identified as a high priority area to be maintained and strengthened.

Consumer participation can be considered at the micro and macro level. At the micro level, it means being actively engaged in clinical service planning and treatment decisions. In other words, it is about being a partner in the clinical process rather than being merely compliant with the clinical decisions made by experts. At the macro level, it means contributing to decisions about the way services operate, including planning and reform processes. Here the consumer or carer is acting not just in relation to personal treatment but to broader processes that impact on larger groups of consumers and carers. In other words, it is a representative role.

Although consumer participation is a worldwide trend for a variety of services, there are three good reasons why it is particularly important in public mental health services and not just a 'passing fad'.

1. There are no 'market signals' for mental health services. In many other kinds of service, the market operates as a protective factor against poor or unresponsive service. If people are unhappy with services, they can move their patronage to that of a competitor. There is little scope for these kinds of responses to inadequate service in public mental health. All monopoly providers carry a particular burden of consultation to counteract the licence to be unresponsive.
2. Consumers of public mental health services often have an ongoing involvement, and the quality and nature of the services they receive might have a disproportionate influence on their global quality of life. Public mental health consumers often identify professionals as the

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people with whom they have the greatest amount of regular interaction and the quality of that interaction can have far-reaching effects.

3. Mental illness is often disempowering and undermines confidence and autonomy. The public mental health service can either reinforce the identity of the consumer as helpless, dependent and with little to offer or it can provide an environment in which the consumer can re-contact or develop capacities for and confidence in decision-making and social engagement.

There exists significant capacity for consumers to influence the types of services they receive. However, given the challenges associated with reform, health services vary in their ability to incorporate new directions into current practices.[1] Changing attitudes of health professionals is crucial in adopting partnership with consumers. It must be recognized by mental health professionals that consumers of mental health services know more than anyone else about what is needed in the planning, development, and management of their care.[2]

This article will explore the challenges of this paradigm shift that is confronting mental health practitioners. It is hoped that it will stimulate health-care providers to reflect on the need for thoughtful, well-reasoned responses to situations that may threaten traditional understandings of practice roles and relationships with consumers.

THE POLICY FRAMEWORK FOR CONSUMER INVOLVEMENT IN SERVICE MANAGEMENT

There are a number of policy documents that guide consumer involvement in mental health service delivery. *National Mental Health Policy* (1992) states that positive consumer outcomes are the first priority in mental health policy and service delivery.[3] The policy suggests that the quality and effectiveness of mental health services are enhanced if the services are responsive to their consumers and communities and if avenues are created for participation in decision-making about the development of services and about an individual's own treatment.[3]

One of the key objectives of the *Queensland Mental Health Plan* (1994) is to ensure that mental health services deliver high quality care that best meets the needs of consumers and that is accountable for the efficient and effective use of resources. This was seen within the planning context of the establishment of formal consumer advisory processes at all levels to ensure participation of consumers and carers in mental health service evaluation and planning.[4] The *Ten Year Mental Health Strategy for Queensland* (1996) again emphasizes formal consumer advisory processes and a push towards the adoption of a consumer-focused service programme.[5]

The *Second National Mental Health Plan* (1998) has, as one of its key priorities for future activity, the development of partnerships in service reform and delivery. This plan states that consumers, families and carers who are key stakeholders must be in a position to influence decisions on all aspects of mental health services and have adequate resources and be assisted to do so.[6]

The *National Standards for Mental Health Services* (1996) are outcome orientated with an emphasis on the end result for consumers and carers.[7] In this document, Standard 3 is about consumer and carer participation and it is stated that consumers and carers are involved in the planning, implementation and evaluation of the mental health service. There are seven criteria related to this Standard, which covers such things as policies and procedures, undertaking a range of activities that maximize consumer and carer participation in the service, training and support, reimbursement, roles and responsibilities and representation.[7]

Another document of interest put out under the National Mental Health Strategy is on education and training partnerships in mental health (1999).[8] In part, this document discusses why service users should be involved. That is, the founding principle of service user involvement in all aspects of mental health services is the notion of participation: the right of people to be agents within the services that affect their lives. This report emphasizes that health professionals need to learn about and value the lived experience of consumers and carers. *Enhancing Relationships between Health Professionals and Consumers and Carers* provides an overview of current issues, policy and initiatives that impact on consumers, carers and health professionals and their ability to work in collaboration.[9]

MAJOR CHALLENGES IN MAINTAINING OR EXPANDING CONSUMER PARTICIPATION

Government policy makes it very clear that mental health services need to adopt a consumer-focused service delivery model. However, there appear to be a number of barriers or obstacles that have impacted upon the extent to which this has taken place.

Perhaps the most significant factor relates to the attitude held by mental health professionals. SANE Australia argued that iatrogenic handicap caused by stigma reinforced by health professionals needs to be recognized as a problem and should be addressed through ongoing consultative engagement with consumers and carers about their experiences.[10]

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Acknowledging personal prejudices is a difficult issue for professionals. This is particularly the case when it is associated with attitudes to treatment that seem altruistic or benign. There is a fine line between the exercise of appropriate care and concern and communicating the message that people with mental illness are unable to make decisions about their own well-being. Professionals may hide behind concepts such as 'duty of care' to actively discourage consumer self-determination.

Taking a symptom management approach to service delivery often results in the person being treated as an illness and not as a person. This approach makes it difficult to focus on empowerment, strengths, client-focused care, participation, and recovery. For many people, these are quite new concepts and are hard to adopt. These new models challenge old constructs. New models require professionals to explore personal concerns over shifts in control, in boundaries, and in the therapeutic use of self.

Staff in mental health services have traditionally been in a position of power and consumers have been passive service recipients. In addition, there has often been a reluctance to include family members or carers in service provision. Carers have not been viewed as a partner with the consumer and service provider and their role is minimized in professional service delivery.[11] Carers for the most part assume the major burden of caregiving and are experiencing undue responsibilities and pressure in their caring roles.[11] Nationally, carers have expressed extremely low levels of satisfaction with service provision in key support areas, such as accessing personal information, emotional and social support, information and education, and consultation by professionals.[11] Carers often see service providers as again hiding behind an apparently benign ethical principle – in this case, confidentiality – to justify not including them in service planning processes. It must be acknowledged that there will be occasions when there are real conflicts between the wishes of consumers and carers, and professionals may view this as a reason for making autonomous and unilateral decisions.

Although subtle forms of prejudice and paternalism are undoubtedly factors in inadequate partnership with consumers and carers, practical considerations are likely to be equally important. Mental health professionals are already required to consult widely as part of working in a multidisciplinary team and their clinical accountabilities are often complex. Key decisions may be made in team meetings or in discussions with senior professionals rather than in consultation with consumers. Consulting with consumers and carers as well as with professional colleagues may introduce a degree of complexity that clinicians judge to be inconsistent with the time they have at their disposal.

In summary, collaboration involves commitment of significant amounts of time to a process that is both ethically and logistically complex.

RECOMMENDATIONS FOR STRATEGIES TO CONSTRUCTIVELY RESOLVE STAFF RESISTANCE

Resolving staff resistance is particularly difficult and has to be worked on from a number of different fronts. Some strategies include the following:

- Building collaboration and partnership considerations into the core clinical accountability processes. In practice, this means that consultant psychiatrists and team leaders must overtly and routinely enquire about collaboration and partnership processes with both consumers and carers in routine review meetings. The multidisciplinary team must be involved in discussion, not just of clinical interventions but of strategies to enhance partnership.

- Making collaboration and partnership indicators a key feature of performance appraisals. Professional seniors and team leaders must be prepared to undertake chart audits and in particular examination of individual service plans to determine not only whether the formalities of partnership, such as consumer signed plans, have been observed but also whether the spirit of collaboration is evident in the form of consumer-appropriate language and appropriate detailing of objectives and strategies.

- Establishing working parties to work on specific aspects of consumer and carer participation. This is particularly timely with accreditation and the push for quality activities and the expectation that mental health services comply with *National Standards for Mental Health Services*. Therefore, it is important to be aware of the relevant policy documents and use your knowledge of them to support the need for consumer and carer participation.

- Establishing programmes and different activities that consumers can participate in so that staff can see the contributions of consumers first hand.

- Forming strong links with the non-government sector – they can be a powerful ally in asserting pressure on the mental health service to increase consumer and carer participation.

- Staff education and training – staff require training in new models of service delivery and these need consumer input so that they can gain a deeper appreciation of the lived experience of consumers.

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PRACTICAL WAYS OF INVOLVING CONSUMERS AND CARERS

There are a number of ways to involve consumers and carers in the delivery of mental health services. This will occur at different levels and may range from eliciting consumers' and carers' views on information provided by the service to having them involved in and directly responsible for aspects of service delivery. Implementation actions may include the following.

Promotional material

Newsletters and leaflets are used to provide consumers with information about services, programmes and access. Consumers have a role to play in ensuring that the information that is provided is jargon-free, clear and concise and is user-friendly.

Service plans

A key shift in new models has been the focus of working with people and identifying what they want from their involvement with the mental health service. Consumer participation in the development of plans for their treatment and care promotes the development of a partnership between the consumer and the mental health service provider. Plans should be free of jargon and clearly document consumer and carer objectives and priorities. Plans should present negotiated solutions to difficult issues such as 'unrealistic' objectives, concerns about risk and tensions between consumer and carer priorities. When mutually satisfactory solutions are not possible, the points of difference should be clearly presented.

Evaluation

Evaluation of what we do is important in ensuring that we are best meeting the needs of consumers and producing quality services. Opportunities should be taken to maximize consumer and carer involvement in the needs analysis and in the monitoring and evaluation process of all the services and programmes that are undertaken by the mental health service. This feedback provides valuable information about what is working well, what requires changes and how services are delivered. While it may be difficult to include consumers and carers in general clinical review processes such as multidisciplinary team meetings, consumer and carer representatives can and should be included in the quality assurance processes of the service.

Consumer and carer surveys

Regular surveys in the inpatient unit and in the community with both carers and consumers should be conducted to determine areas where service delivery could be improved. Telephone surveys and satisfaction surveys are two means by which this information can be obtained. This information can be used as a basis to establish a working party to progress suggestions that have been identified. Surveys must be judged not on the fact that they happen but on response rate and success in eliciting concerns and providing a basis for service improvement. Surveys that have low return rates and bland results are little more than tokenism. From time to time, an independent telephone survey should be commissioned. Consumers are often better able to articulate issues by telephone than by mailed survey and are more willing to speak openly to someone who is not part of the service.

Consumer and carer forums

Public meetings or forums with consumers and carers should be held on a regular basis. This works both to update consumers and carers about the service and to gain their feedback about issues or concerns that they may have and ideas they may have as priorities for future action.

Committee membership

Committees responsible for decision-making about how the mental health service runs and for making decisions about future directions for service delivery need to have mechanisms in place to ensure that the consumer and carer voice is represented. An example is having a consumer and carer consultant sit on the committee and having consumer and carer feedback as a regular agenda item.

Staff and consultants

In some instances, staff positions may be created for consumers to work as project officers, for example, to coordinate implementation of consumer and carer participation. Alternatively, consumers and carers may be hired as consultants to provide specialized consumer-focused advice and training to service providers. Advice may focus on policy, management and quality of service to mental health service providers, service review and development, and quality and service audits for providers.

Staff training

Having consumer and carer input into the ongoing training courses for mental health professionals will assist them to understand the lived experience of consumers and the impact that the illness has had on their lives. Training aspects may include education in recovery principles and skills for people who experience mental illness, training in recovery competencies for mental health workers, providing training for trainers in the recovery approach, and lectures and workshops about mental health issues.

Promotion, prevention and early intervention

Key themes in the *Second National Mental Health Plan* are promotion, prevention, and early intervention for mental health. Consumers place importance on this approach to mental health issues rather than waiting until a situation requires action be taken.[6]

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This provides many opportunities for staff and consumers to work together on projects to assist in the development of initiatives that improve or enhance the mental health and well-being of individuals and communities.

Research and evaluation

It is necessary that mental health services are able to demonstrate to individual consumers, carers and other service providers that the work undertaken contributes to better outcomes for the consumers who use the service. Consumers need to be consulted about what research questions they would like answered and participate in the research process. For example, they might have input into survey design or assist in conducting the research carried out from within the mental health service.

Programme development

It is important to be able to ascertain the domains that are of particular importance to different consumers so that these can be addressed in interventions designed to promote recovery.

RECRUITING AND RETAINING CONSUMER AND CARER REPRESENTATIVES

Services need to be active in recruiting consumers and carers for representative roles within the service. This means letting people know that consumer and carer representation is welcomed, and providing a point of contact and opportunities for induction into the role. If the service takes a rather passive approach, it will find that those who put themselves forward are the more outgoing or aggrieved. These are important people and must be nurtured but services should also endeavour to identify and recruit 'low profile' people who have a real interest in service development.

Beyond recruitment, the most important thing is to give consumer and carer representatives support and to provide opportunities for ongoing education and training. The consumers and carers need to feel valued and that they have a meaningful role to play. It is important to respect the consumer's comfort level and not require them to do things that may cause them feelings of discomfort.

At the micro level, mental health consumers and carers, like many of the professionals that they are involved with, often have little experience in either sharing decisions around their treatment or in health planning. Collaboration is therefore a learning process for both. At the macro level, consumers and carers need to have the opportunity to learn about how decisions are made and how they can effectively contribute. Consumers and carers require assistance from professionals to negotiate the system, to develop skills, and to have ongoing support. This could include supervision, a clear statement of roles and responsibilities, clear lines of accountability, and access to resources.

CONCLUSIONS

Mental health consumers have a unique contribution to make to the improvement of the quality of mental health services. The significance of their unique contributions stems from the expertise they have gained as recipients of mental health services. Their contribution should be valued and sought in areas of programme development, policy formulation, programme evaluation, research, quality assurance, and education and training of mental health services staff. We suggest that it is time to move beyond paying lip service to consumer and carer participation and actively explore strategies to increase their participation in a meaningful way.

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