



## The myth of representation: The case for consumer leadership

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### Abstract

Australian government policy now embodies a clear expectation that consumers should be participants in all aspects of mental health services. A number of barriers have been identified as inhibiting the realisation of this goal, with the negative attitudes of professional staff being recognised as a major factor. A more pervasive barrier with the potential to minimise the positive developments in consumer participation is the issue of representation. It has been claimed that consumers who are actively involved in participatory roles are not necessarily representative of the broader population of mental health consumers. The paucity of literature makes this argument difficult to either defend or refute, although there is limited research evidence to suggest that the views of active consumers may indeed be similar to those who do not choose to have involvement. The aim of this paper is to consider the implications of engaging in debate about the extent to which consumer advocates might represent a broader group. In particular the potential consequences of this argument include: silencing activism; questioning the legitimacy of consumer roles; and, discriminatory expectations of consumers. These issues are discussed with the aim of establishing the need to use the term consumer leadership to describe participation which is aimed at the systemic level.

### Keywords

*consumer, consumer representation, consumer leadership, mental health services*

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### Introduction

The broad and far-reaching policy changes in Australia during the 1990s have clearly articulated the requirement that mental health services encourage the participation of consumers in the development, implementation, delivery and evaluation of the services (Australian Health Ministers, 1992, 1998, 2003; Commonwealth of Australia, 1997).

To support the implementation of the policy directives a number of initiatives have been instituted, including the employment of mental health consumers as employees of mental health

services to provide consultancy to those service in relation to consumer perspective (Meehan, Bergen, Coveney & Thornton 2002; Roper, 2003a).

A number of barriers to effective consumer participation have been identified. The negative attitudes of mental health professionals are considered as a major detractor for effective participation (Caldwell & Jorm, 2001; Connor, 1999; Deakin Human Services, 1999; Epstein & Olsen, 1998; Gordon, 2005; Lloyd & King, 2003; Meehan, et al., 2002; Middleton, Stanton & Renouf, 2004; Sangster, 1999; Tobin, Chen & Leathley, 2002). The lack of systemic

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- Citation:** Happell, B. & Roper, C. (2006). The myth of representation: The case for consumer leadership. *Australian e-Journal for the Advancement of Mental Health*, 5(3), [www.auseinet.com/journal/vol5iss3/happell.pdf](http://www.auseinet.com/journal/vol5iss3/happell.pdf)
- Published by:** Australian Network for Promotion, Prevention and Early Intervention for Mental Health (Auseinet) – [www.auseinet.com/journal](http://www.auseinet.com/journal)  
Received 17 July 2006; Accepted 27 October 2006.

approaches to facilitate consumer roles has also been raised but specific emphasis placed on the lack of adequate training and supports for these roles (Bjorklund & Pippard 1999; Meehan et al., 2002; Middleton et al., 2004; Roper, 2003a; Sangster 1999).

### **The issue of representation**

Concern has been raised at service delivery level, that the views of consumers employed as consultants or otherwise actively engaged in consumer participation activities may indeed not be representative of the wider population of mental health consumers (Crawford, Aldridge, Bhui et al., 2003; Crawford & Rutter, 2004; Rutter, Manly, Weaver et al., 2004; Tobin et al., 2002). Crawford and Rutter (2004) argue:

*Some service users feel that because users [consumers] who take part...are unlikely to represent the views of ordinary patients, the views put forward by users groups should not carry weight or influence when planning changes to services. (p. 562)*

Warning about the issue of representation in the Australian consumer movement was sounded in the following statement:

*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? (Tobin et al., 2002, p.98).*

In the absence of further clarification it can only be assumed that the authors consider that consumers currently participating in mental health services may do so as a means to pursue their own needs or interests rather than to represent the larger group of people who are using, have used, or will use (or attempt to use), mental health services in the future.

Crawford and Rutter (2004) conducted research to determine the extent to which the views of members of an established mental health consumer group were representative of a broader patient group. Participants were asked to rate the importance of specific priorities for service developments. The results demonstrated considerable similarity in ranking of priority areas with the same priorities being identified by the two groups. The main difference between responses was that consumer group members placed slightly higher importance on each of the priorities than did other consumers.

The generalisability of these findings is limited by the collection of data in one geographic area of the United Kingdom. However this provides impetus to question any automatic assumption that the views and opinions of those consumers who actively participate, are potentially out of step with the views and opinions of those who do not (Crawford & Rutter, 2004).

While such findings may be used to counteract arguments posed by service providers, might this in fact divert the issue away from challenging the concept of consumers as representatives as a discriminatory and patronising view of the nature and importance of consumer participation in mental health care? The aim of this paper is to critique the concept of representation on the basis that extent to which mental health professionals are representative of their broader groups is rarely, if ever, called into question.

### **Distinguishing between types of consumer participation**

#### ***Individual treatment***

Arguments around the extent to which consumers currently participating within mental health services are representative fail to delineate between two fundamental definitions of consumer participation. Participation refers on the one hand to individual participation in treatment, and on the other hand in 'service reform' activities. This distinction is clearly articulated by Lloyd and King (2003) through their description of micro and macro level participation:

*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. (p.180)*

In the case of the micro, the issue of representation is clearly not relevant, particularly when emphasis is placed on the need for care to be individually based.

The individual can participate in care by making decisions about treatment (e.g. indicating a

preference for one pharmaceutical agent over another, or seeking non-pharmaceutical agents as complimentary or an alternative to conventional medicines), or registering a complaint about treatment (e.g. an appeal against involuntary detention). In such a case any 'sectional' interests (Tobin et al., 2002) will be, quite rightly, their own.

### ***Consumer participation in service reform (or systemic advocacy)***

This refers to activities directed at service reform. Mechanisms for such activities in Victoria have been Area-based Consumer Consultancy and independent consumer perspective activities such as the education and training of the mental health practitioner workforce, advising on quality of services received, contributing to how services should be evaluated, influencing policy at program and political levels, systemic advocacy at local Area Mental Health Services as well as state and national levels.

There is also work being done by service users in the Psychiatric Disability Support Sector (PDSS) at the level of running groups, determining what activities should be run, operating services out-of-hours and/or operating additional services to those run by 'qualified' staff, and advising on the quality of services received. These activities plus a plethora of others occur in a range of settings as diverse as 'drop in centres' to accommodation services.

When the issue of representation is applied to systemic advocacy, it suggests that consumers who are actively involved in participation in order to seek change at a systemic level may be inconsistent with the views of the majority of service users, who do not choose to be active participants.

### **Negative consequences of the representation argument**

Such a view, while superficially logical, is at best potentially damaging to the consumer participation movement and at worst blatantly discriminatory, specifically because it:

- is a method to silence activism;
- undermines the legitimacy of consumer roles; and
- requires consumers to justify themselves in a way that mental health professionals are not.

### ***Silencing activism***

Suggesting that consumer activists are not (or potentially not) representative of the wider population of consumers, diminishes the importance of what they say. It is reduced to the view of an individual or small number of individuals, and is therefore less important. This is particularly evident where activists are vocal. Here we have the 'loudmouth consumer' (someone obviously no longer in need of protection) as an oppressor of the 'real consumers' (who must still need provider protection).

The activist is painted as having an axe to grind rather than a legitimate point to make. Furthermore, this suggestion does not acknowledge the fact that loud protestation is often a result of inadequate audience. Many of those loud/sectional voices are calling for long overdue action on behalf of their brethren. Suggesting that such activists are not representative of consumers will do little to open the lines of communication and encourage greater participation (Roper, 2003b).

### ***Questioning the legitimacy of consumer roles***

The lack of clarity around the meaning of 'sectional interests' in relation to consumer participation (Tobin et al., 2002) makes it difficult to clearly identify the issues and refute them accordingly. However, currently in Victoria as well as other parts of Australia, consumers are employed as consultants in mental health services (Department of Human Services, 2003; Meehan et al., 2002; Middleton et al., 2004; Roper, 2003a). The consumer consultant positions were implemented in order to introduce consumer perspective into mental health services, increase the responsiveness of services to consumer needs, and, provide a voice for consumers within mental health services (Department of Human Services, 2003).

The description of consumer consultant positions does not include a requirement that they be representative (Department of Human Services, 2003). 'Consultant' is defined as the provider of expert or professional advice: 'a person who facilitates organisational change and/or provides subject matter expertise on technical, functional and business topics during development or implementation' ([dictionary.reference.com](http://dictionary.reference.com)). The

consumer consultant is therefore employed on the basis of his or her expertise gained through experience of the mental health system. The role of the consumer consultant is intended to directly advance the concerns of service users. This requires that they consult widely, and articulate the first person experiences of services. It does not mean that they speak for them or be required to demonstrate their representation of consumers any more than any consultant should be required to demonstrate their representation of their constituents.

Furthermore, consumer consultants are generally employed on a small time fraction (Middleton et al., 2004) and given the expectations that they become actively involved in systemic advocacy (through committee membership, selection panels, education and training, for example) there is insufficient time available to enable consumer consultants to speak for the majority of service users, if even this was considered appropriate.

There also appears to be an apparent contradiction in mental health services employing consultants to seek feedback about the services from those who receive them, only to subsequently dismiss the information as provided as sectional or anecdotal, particularly if the resources provided are not adequate to achieve the goal (Middleton et al., 2004; Roper, 2003b). Such a stance diminishes the legitimacy of the consumer consultant role.

The same principle would apply to other consumer roles that have developed and hopefully will continue to develop in the future. The introduction of a consumer academic role in Victoria, Australia (Happell & Roper, 2003) provides an opportunity for consumer perspective to influence an academic department and in particular to shape the attitudes of psychiatric nurses towards a more positive understanding of consumer participation.

If it were suggested that a consumer academic should solely represent the views of the broader consumer group, we would surely be discriminating in light of there being no similar requirements for academics from other health professions. This would deny a fundamental right to academic freedom. Although there is no clear definition of academic freedom it 'is seen

within universities as a fundamental right allowing faculty to comment on and study any topic in an unfettered way' (Wright & Wedge, 2004, p.795). The importance of academic freedom is embodied in 'the relentless, objective, scholarly pursuit of knowledge and truth for the advancement of the human condition' (Wright & Wedge, 2004, p.795). In order to advance the cause of consumer perspective therefore, the consumer academic has a leadership role, which would be significantly hindered by a perceived need to be representative of consumers as a whole.

The success of future innovative roles for consumers will depend at least in part on the implementation of strategies to enhance success. Negation of the need to be representative is an important part of this process.

#### *Discriminatory expectations of consumers*

The suggestion that consumers who engage in systemic participation in mental health services should be representative, calls upon them to justify themselves in a way that has not been expected of mental health professionals. The experience of the authors has been that when professionals are selected to sit on committees, working parties or interview panels within services, it is generally based on their level of seniority within the organisation. In itself this calls into question the extent to which they are representative of their profession as a whole. There are no known processes in existence to ensure that these individuals canvass the views of the broader professions of which they are a member.

At the State and National policy level, the authors were unable to find any clear guidelines for the selection of committee members. Members are often sought as representatives of specific professional or industrial organisations. While it is not the intention to question the validity or otherwise of these processes, the degree to which such an individual is in fact representative of their profession is worthy of consideration.

There is considerable variation in the proportion of professionals that choose to be members of their professional body. To use mental health nursing in Australia as an example, in 2003 there were 12,383 nurses working in this specialist

field. In analysing the membership figures for the Australian and New Zealand College of Mental Health Nurses, less than 20% of these nurses were members. How then can a person selected to represent this organisation be considered as a representative for mental health nurses in Australia? Caldwell and Jorm (2000) acknowledge that a limitation of their research into mental health nurses' attitudes towards people with mental illness was created by sampling nurses from the professional body membership base. The authors state that the views of these nurses may not be generalisable to the broader profession of mental health nursing.

Furthermore, there is little evidence to suggest that professional bodies are indeed representative of their own members. A review of the minutes of the Victorian Branch of the Australian and New Zealand College of Mental Health Nurses indicates that there are rarely more than twenty members present at one time (representing less than 10% of the total membership for the state). Over a one year period attendance records show approximately 30 people attended one or more meetings. How then can a representative of this organisation be confident that they represent members, let alone nurses more broadly?

To suggest, therefore, that the voice of consumer activists or advocates should be less influential unless it can be demonstrated to be representative, is tantamount to discriminating against a group that is already marginalised and subject to the stigmatising attitudes of mental health professionals (Caldwell & Jorm, 2001; Connor, 1999; Deakin Human Services, 1999; Meehan, et al., 2002; Middleton et al., 2004; Sangster, 1999; Tobin et al., 2002).

### **Representing consumers: Whose responsibility?**

The representation of a broad range of consumer interests remains a laudable goal within Australian Mental Health Services. The achievement of this goal would become more likely with the clear recognition of the need for separation between consumer advocacy and the responsibility of mental health services to ensure they are meeting the needs of service users.

In recognition of the need to establish the effectiveness of mental health services, Australian mental health services have undertaken a widespread campaign to introduce the use of routine outcome measures (Coombs & Meehan, 2003). This reflects an identified need for local strategies developed by service users to evaluate the utility and effectiveness of mental health services (Oades, Viney, Malins et al., 2005). However, the degree to which the measures chosen are appropriate has been called into question.

Evidence indicates that consumers do not consider that the selected measures address the issues they consider to be most relevant (Campbell, 1998; Fossey & Harvey, 2001; Graham, Coombs, Buckingham et al., 2001; Miller, Siggins, Kavanagh, & Donald, 2003). Furthermore, findings from consultancies commissioned by the Victorian government suggested the development of alternative strategies to assess consumer outcomes and emphasised the need for consumer involvement and collaboration in the development of these strategies (Graham et al., 2001; Miller et al., 2003).

Despite disagreements about the choice of outcome measures, Australian governments have recognised their responsibility for determining the effectiveness of services. Indeed consumer advocates could play an instrumental role in lobbying for the development of outcome measures that more accurately reflect what consumers are seeking from mental health treatment. This process could increase confidence within mental health services that they are able to achieve a more representative view without threatening the potential benefits associated with consumer participation at a systemic level.

By accepting that it is their responsibility to determine effectiveness, mental health services could commence the process of working in partnerships with consumer consultants and advocates to ascertain the most appropriate means to establish the effectiveness of service delivery. This would potentially create a more harmonious relationship where service providers do not dismiss the contributions of consumers as unrepresentative.

## Towards a model of leadership

Gordon (2005) describes a recent trend in New Zealand mental health services to move from consumer participation to consumer leadership. Recommendations included in the unpublished report recommending inclusions to the Second Mental Health Plan include strategies to promote consumers as leaders through:

- central leadership in the managerial and governance structures that plan, fund and deliver mental health services;
- the provision of service user managed and delivered services; and
- central involvement of service users in mental health advocacy, training, education and promotion (p.365).

Gordon (2005) clearly articulates the importance of embodying leadership in order to promote genuine and effective participation in mental health care delivery, as indicated by the following statement:

*...the paradigm shift from consumer 'participation' to consumer 'leadership' may be more fruitful in realising the considerable benefits that result from effective consumer involvement in mental health services (p.365).*

The importance of leadership to mental health consumers, however, goes beyond the benefits portrayed by Gordon (2005). By identifying the existence of consumers as leaders, there is acknowledgement of a movement to be led, of interests to be served. The consumer leader is likely to command more status, which is likely to provide the basis to advance consumer participation far more than has been possible to date.

Acceptance of the concept of consumer leadership will also clearly highlight the lack of relevance of the argument that consumer participation should be seen to be representative in order to be truly valuable. While the terms leadership and representation are by no means incompatible, leadership is not bound with the need to be representative. The following definition by Senge (1990) describes leadership as:

*the capacity of a human community to shape its future and to sustain the significant processes of change required to do this shaping. Leadership grows from the capacity to hold creative tension; the energy generated when people articulate a 'vision' and*

*articulate the current reality and status in an honest way (to the best of their ability).*

Leadership therefore requires more than the capacity to know and represent the interests of the broader group, it requires creativity and vision and may indeed involve exposing others to ideas and concepts they have not previously considered or known. Consumer leaders can be those who strive towards the achievement of a mental health service that provides clear opportunities for consumers to participate in mental health service delivery on an individual and (if desired) a systemic level. Consumer leaders can hold roles within mental health services, academic institutions and government departments.

Within this model of consumer leadership, the issue of ensuring that the voice of all consumers is heard by mental health services becomes the responsibility of all leaders not merely that of those consumers who choose to participate.

## Conclusions

Consumers of mental health services are already subject to more discrimination than other minority groups, with mental health professionals being no exception to this practice. If the goals of contemporary mental health policy in Australia are to be realised, all possible efforts must be made to minimise or negate the impact of identified barriers. Some criticism of current trends in consumer participation has been raised with the suggestion that consumers actively involved in participatory activities may not be representative of the broader group of consumers.

To suggest that consumers should be representative, whether intentionally or otherwise, has the potential to undermine advocacy activities and the legitimacy of the roles occupied by consumers currently or those which might be developed in the future. Furthermore, suggesting the need for consumers to demonstrate their representation of the broader field is creating an expectation unparalleled within professional groups.

The use of the term 'participation' to describe both involvement in individual care and contributions aimed at a more systemic level, has possibly inadvertently added to this confusion. The use of the term 'consumer leadership' is a

more accurate description of systemic participation. In doing so, this language can contribute to acknowledgement of, and respect for, consumer leaders and remove focus on the issue of representation as an unnecessary divergence within the discussion of consumer participation in mental health care. In this context consumers participate in mental health services as individual recipients and as leaders.

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