

Current Perspectives on Consumer Participation among Non Government Drug and Alcohol Service Staff in New South Wales

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Abstract

In Australia the successful implementation of consumer participation programs in mental health has demonstrated consumer participation to be achievable, particularly within other marginalized groups of people. The context of drug and alcohol services brings with it particular sensitivities and complexities, and these can present some challenges to implementing consumer participation. The aims of this study were to explore staff opinions current activities, attitudes and challenges in implementing consumer participation models in non government drug and alcohol services in NSW. A semi structured survey was developed, consisting of questions around service user participation, and was sent to non government alcohol and other drug services in New South Wales, Australia. The majority of services reported that they currently engage in some form of consumer participation, however many were unlikely to engage in activities that involved consumers and staff working cohesively together where consumers' perspectives are equal with those of staff. Despite this, most respondents believed their service could benefit from implementing consumer participation into planning and policy development. Over half the sample agreed that a main barrier to implementing consumer participation activities in their service was around staff concerns that they could not trust service users and that service users would have access to confidential information. Consumer participation has the potential to benefit those who plan and provide health care services, as well as patients who use the service. For staff and service users within the drug and alcohol sector to more successfully implement consumer participation, consumers and staff need to develop a stronger shared trust.

Keywords: Consumer participation; Drug and alcohol; Health services; Australia

Introduction

Consumer participation in healthcare services has been previously defined as the "process of involving health service users in decision making about health service planning, policy development and quality issues in the delivery of health services" [1]. Consumer participation can range from 'low'-level information provision and consultation, to 'mid'-degree involvement of consumers in non decision-making activities, to 'high'-degree shared decision-making [2]. Overall, consumer participation promotes patient's interests, and seeks a partial redistribution of power between health practitioners and service users [3]. One particular group of people whose views and experiences have traditionally been disvalued and excluded by health care services, who could benefit from the implementation of consumer participation are people who use drugs and alcohol. Research indicates that negative attitudes of health workers towards people who use drugs and alcohol may be one possible reason for their exclusion from actively participating in their service provision. For example, in a study by Ross and Darke health workers beliefs about people who inject drugs (PWID) were related to the idea that injecting drug use was an indication of personal inadequacy and criminality [4]. Furthermore, health workers have previously reported that PWID are often their most difficult clients, as they expect them to be more dangerous, less cooperative and less truthful [5,6].

The context of drug and alcohol services brings with it particular sensitivities and complexities, and these can present some challenges to

implementing consumer participation. For both service staff and clients there are a range of issues related to a lack of experience and confidence in participating in consumer participation activities [7]. Additionally, service providers have previously expressed concerns that drug dependence itself, and the 'chaotic' nature of some drug users' daily lives, may limit the capacity of clients to engage in consumer participation [7,8]. According to Tuana marginalized communities such as people who use drugs and alcohol are often judged as not being "epistemically credible because they are constructed as being suggestible, gullible or vengeful" [9]. However, it is possible for people who use drugs and alcohol to re-define themselves as 'able' and challenge the perspective of some service providers that the chaotic nature of some drug users' daily lives acts as a barrier to consumer participation. People who use drugs and alcohol can do this by demonstrating that a chaotic lifestyle is not in and of itself a hindrance to knowing what their health care needs are.

Currently there are varying levels of consumer participation in the drug and alcohol sector across New South Wales (NSW). Although consumer participation is widely discussed as important and desirable, there is scant literature that examines the implementation of consumer participation in drug and alcohol services [10]. The Australian Injecting and Illicit Drug Users League (AIVL) conducted study on consumer participation in treatment services and found that although services believed in the principle of consumer participation, they expressed concerns around implementing consumer participation [11]. Such findings suggest that more research is required to understand the complex issues regarding the design and implementation of consumer participation in drug and alcohol services specifically, understanding the patterns and dynamics of staff attitudes to better plan and support

consumer participation. The aim of this exploratory study was to explore current activities, attitudes and challenges in implementing consumer participation in non-government alcohol and other drug services in NSW, Australia.

Method

A survey was sent to non government alcohol and other drug services in NSW. The survey aimed to assess views on consumer participation, understandings of models of consumer participation, current practices and initiatives around consumer participation in the service, concerns about implementing consumer participation and models of best practice for that service. A reminder was sent to all non-responding organisations after 3 weeks to try and increase the response rate.

Respondents were asked about the availability of consumer participation activities at their service as well as future consumer activities the service would be interested in implementing. These questions were closed-ended and dichotomous (yes/no). Respondents were also asked questions regarding opinions about consumer participation, and about the barriers to conducting consumer participation. For these questions multiple response options were presented in the form of a five-point Likert scale (strongly agree, agree, neither agree nor disagree, disagree, strongly disagree). Data was

analysed using SPSS version 19. The study received ethical approval from the human research ethics committees at the University of New South Wales.

Results

The survey instrument was sent to 128 staff at a variety of non government alcohol and other drug services. Sixty participants completed the survey (47% response rate). Over half of respondents reported the main focus of their service to be on drug and alcohol health promotion (60%), followed by residential rehabilitation (46%) and non-residential rehabilitation (40%) (answers were not mutually exclusive). Over a third of respondents reported that their service primarily targeted adults (35%).

Just over 80% of respondents reported that their service currently engages in consumer participation. Of the respondents who reported that their service currently engages in consumer participation (n=51), nearly 95% noted that these activities included conducting surveys on services and programs amongst consumers and/or implementing a consumer complaints procedure, respectively (Table 1). Very few respondents, around 1 in 10, noted other staff-related activities as including consumer representation. As such, few consumers were represented in activities such as participation in staff performance appraisal or in staff recruitment (Table 1).

	n (%)
Service user participants involved in staff performance appraisal	6 (11.8)
Service user participants involved in staff recruitment	7 (13.7)
Service user participants involved in service planning committee	22 (43.1)
Service user participants regularly attending staff meetings	11 (21.6)
Service user participants involved in staff training	13 (25.5)
Service user participants involved in resource development	35 (68.6)
Service user participants are supported to conduct their own group activities	37 (72.5)
Service displays user group publications	25 (49.0)
Councils or forums for service users to express opinions about quality of service	37 (72.5)
Conduct surveys on services and programs amongst service user participants	48 (94.1)
Service user participants involved in writing or producing brochures, fact sheets or educational resources written or produced by this service	23 (45.1)
Service user complaints procedure	48 (94.1)
Suggestion box in service	34 (66.7)
Strategies for promotion and implementing information on service user participation to service users	28 (54.9)
Service user representation policy	12 (23.5)
Evaluation of service user representation (e.g., feedback, reporting, monitoring)	39 (76.5)
Note: Percentages do not add to 100%. Answers were not mutually exclusive	

Table 1: Consumer participation activities currently conducted by respondents' services (N=51).

Furthermore, consumers' involvement in staff performance appraisal, staff recruitment and attendance at staff meetings were activities least likely to be reported by respondents as activities their

service would like to implement (Table 2). While just over 60% of respondents either agreed or strongly agreed that a main barrier for implementing consumer participation was that staff would not like

engaging in consumer participation if the consumers had access to confidential information.

	n (%)
Service user participation incorporated into the vision or mission statement of the service	26 (43.3)
Charter of client/patient rights (a document outlining client/patient's rights and the guarantees that specify service conditions)	17 (28.3)
Service user participants involved in staff performance appraisal	9 (15.0)
Service user participants involved in staff recruitment	9 (15.0)
Service user participants involved in service planning committee	22 (36.7)
Service user participants regularly attending staff meetings	9 (15.0)
Service user participants involved in staff training	15 (25.0)
Service user participants involved in resource development	25 (41.7)
Service user participants are supported to conduct their own group activities	16 (26.7)
Service displays user group publications	13 (21.7)
Councils or forums for service users to express opinions about quality of service	21 (35.0)
Conduct surveys on services and programs amongst service user participants	15 (25.0)
Service user participants involved in writing or producing brochures, fact sheets or educational resources written or produced by this service	21 (35.0)
Service user complaints procedure	13 (21.7)
Service user complaints procedure	18 (30.0)
Strategies for promotion and implementing information on service user participation to service users	25 (41.7)
Service user representation policy	29 (48.3)
Evaluation of service user representation (e.g., feedback, reporting, monitoring)	21 (35.0)
Note: Percentages do not add to 100%. Answers were not mutually exclusive	

Table 2: Consumer participation activities respondents' services would like to implement (N=60).

Overall, the majority (78.3%) of respondents reported that they believed their service could benefit from implementing consumer participation into its planning and policy development. However, less than half of respondents wanted service users to be involved in the way services and programs are run. Furthermore, While 72% of respondents either strongly agreed or agreed that their service quality would be improved if consumer's opinions about services were included, less than half of respondents either strongly agreed or agreed that consumers of their service are reliable enough to be involved in deciding or planning how services are run (Table 3). Just less than half of respondents either strongly agreed or agreed that their service should hold open meetings to get consumers views on how the service should be run.

Discussion

One of the main findings from the survey was that although the majority of respondents believed their service could benefit from implementing consumer participation, less than half of respondents wanted service users to be involved in the way services and programs are run.

The majority of services reported that they currently engage in some form of consumer participation, however many were unlikely to have implemented, or plan to implement, consumer participation in activities that involved staff assessment or employment, such as open forums, recruitment and/or appraisals.

Respondents who agreed or Strongly agreed that:	n (%)
Service quality would be improved if service users opinions about services were included	43 (71.7)
Service users should be included on committees that decide or plan how services are run	39 (65.0)
This service should hold open meetings to get service users views on how the service should be run	28 (46.7)

This service would respond to suggestions offered via a suggestion box	45 (75.0)
Service users complaints about the quality of services are usually reasonable	34 (56.7)
Service users are generally interested in being involved in deciding or planning how services are run	29 (48.3)
Service users of this service are reliable enough to be involved in deciding or planning how services and programs are run	27 (45.0)
Service users are not too busy to be involved in deciding or planning how services and programs are run	26 (43.3)
Staff want service users to be involved in the way services and programs are run	25 (41.7)
Service users outcomes/treatment would improve if service user participation was implemented	38 (63.6)
Note: Percentages do not add to 100%. Answers were not mutually exclusive.	

Table 3: Respondents' attitudes towards consumer participation (N=60).

This suggests that services are more willing to implement low or mid degree activities than high degree activities, which may require consumers and staff to work cohesively together in a team environment where consumers' perspectives are equal with those of staff. More so, staff may feel apprehensive about consumers' ability to undertake tasks associated with high degree activities. When services were asked about the main barriers for implementing consumer participation, consumers' access to confidential information was one of the main barriers, along with a lack of trust by staff of consumers' managerial capabilities within the organization. Less than half of the service staff agreed that consumers were reliable enough to be involved in deciding or planning how services are run. This finding was also revealed in the TSU project with providers sighting the inadequacy of clients' skills and concerns around confidentiality of staff as grounds for their reluctance to involve clients in such administrative matters [11].

While this research is based on a limited health worker sample, the findings still provide some important insights into the differences between thoughts about the benefits of consumer participation and barriers to its practical implementation. Looking at the current implementation of consumer participation in non-government drug and alcohol services in NSW, it appears that some services are not instituting a high level of consumer participation due to lack of trust in their consumers and belief that consumers may not be capable of such responsibilities or adequately able to inform on service activities in ways that may be beneficial. Previous studies have shown that while health workers have an overall positive attitude towards peer workers, health workers with a less permissive attitude towards PWID were likely to have a more negative attitude toward peer workers [12]. It is worth exploring the idea that such negative attitudes may pose a barrier to the success of consumer participation by undermining consumers' efforts and fostering a non-supportive or even threatening environment. Currently, it may be that service providers do not perceive consumers as credible because by the very nature of their drug use, they are seen as incapable, untrustworthy or unreliable [13]. These views could be subtly communicated to consumers and undermine their confidence to engage with and undertake consumer participation activities.

Consumer participation has the potential to benefit those who plan and provide health care services, as well as patients who use the service [14]. Service staff reported that they saw the overall benefit of implementing consumer participation and in particular valued having

the voice of someone who actually uses, or has previously used the service, to better understand how the service was perceived. Consumer involvement in other health sectors, such as mental health, has contributed to a range of improvements, including the increase of service accessibility, and providing psychosocial benefits to consumers [10,15,16].

For drug and alcohol health services and for people who use drugs and alcohol to benefit from consumer participation, consumers and service providers need to develop a greater shared trust which will result in a partial redistribution of power between drug and alcohol service providers and consumers. This will help to enable the implementation of higher level consumer activities and assist in consumers feeling that their input is valued.

Government, peak organizations and consumer based organizations have a responsibility to assist and support consumers and services providers during this process. There may be a range of benefits for people who use drugs and alcohol merely by feeling that they have a voice in their own treatment and service provision, including possible increases in service accessibility, treatment retention and a decrease in recidivism.

References

1. Consumer Focus Collaboration (2001) Consumer participation in accreditation. Commonwealth Department of Health and Aged Care, Canberra.
2. Bryant J, Saxton M, Madden A, Bath N, Robinson S (2008) Consumers' and providers' perspectives about consumer participation in drug treatment services: Is there support to do more? What are the obstacles? *Drug Alcohol Rev* 27: 138-144.
3. Williamson C (1999) Reflections on health care consumerism: insights from feminism. *Health Expect* 2: 150-158.
4. Ross MW, Darke S (1992) Mad, bad and dangerous to know dimensions and measurement of attitudes toward injecting drug users. *Drug Alcohol Depend* 30: 71-74.
5. Brener I, von Hippel W, Kippax S, Preacher K (2001) The role of physician and nurse attitudes in the health care of injecting drug users. *Subst Use Misuse* 45: 1007-1018.
6. McLaughlin D, McKenna H, Leslie J (2000) The perceptions and aspirations illicit drug holders hold towards health care staff and the care they receive. *J Psychiatr Ment Health Nurs* 7: 435-441.
7. NSW Department of Health (2005) A guide to consumer participation in NSW drug and alcohol services. NSW Department of Health, Sydney.

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8. Fischer J, Neale J (2008) Involving drug users in treatment decisions: an exploration of potential problems. *Drug-Educ Prev Polic* 15: 161-175.
 9. Tuana N (2006) The Speculum of ignorance: The women's health movement and epistemologies of ignorance. *Hypatia* 21: 1-19.
 10. Crawford M, Rutter D, Manley C, Weaver T, Bhui K, et al. (2002) Systematic review of involving patients in the planning and development of health care. *BMJ* 325: 1263-1267.
 11. Australian Injecting and Illicit Drug Users League (2011) Treatment Service Users Project: Phase Two Final Report. Australian Injecting and Illicit Drug Users League, Canberra.
 12. Resnick I, Brener L, Treloar C, Hull P (2012) Health workers attitudes towards peer workers in hepatitis C prevention. *Psychol Health Med* 17: 659-666.
 13. Code L (1987) *Epistemic responsibility*. University Press of New England, Hanover.
 14. Brener L, Resnick I, Ellard J, Treloar C, Bryant J (2009) Exploring the role of consumer participation in drug treatment. *Drug Alcohol Depend* 105: 172-175.
 15. Butterworth M, Livingston G (1999) Medical student's education: the role of caregivers and families. *Psychiatr Bull* 23: 549-551.
 16. Stacy R, Spencer J (1999) Patients as teachers: A qualitative study of patients' views on their role in community based undergraduate project. *Med Educ* 33: 688-694.