Consumers’ and providers’ perspectives about consumer participation in drug treatment services: is there support to do more? What are the obstacles?

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Abstract

Introduction and Aims. Implementing consumer participation initiatives in Australian drug treatment services successfully is predicated on the support of those most centrally involved. This paper describes service providers’ and consumers’ (1) beliefs about and commitment to consumer participation; and (2) perceived barriers to conducting or participating in consumer participation. Design and Methods. Data were collected from 64 providers and 179 consumers of drug treatment services. Results. The data showed that almost all consumers (89.9%, n = 161) and providers (84.4%, n = 54) believed in the principle of consumer participation (that consumers’ views should be included in service planning and delivery) and a large proportion would be willing to conduct or participate in consumer participation activities in future. Providers were less supportive of activities in which consumers would be involved in decision-making that relates directly to staff (such as staff training, recruitment and performance appraisal), and expressed concerns about the practicality of operationalising such activities, the inadequacy of consumers’ skills, consumers’ lack of interest and the appropriateness of having consumers involved in such decision-making. A small proportion of consumers also indicated that they did not want to participate, expressing beliefs that it was not their place to be involved and that they lacked the required skills. Conclusions. Overall, these findings revealed that there was considerable support for the further development of consumer participation in drug treatment services, but the predominant obstacle was the view that it is not consumers’ place to take part, and that they lack the interest and skills to do so. [Bryant J, Saxton M, Madden A, Bath N, Robinson S. Consumers’ and providers’ perspectives about consumer participation in drug treatment services: is there support to do more? What are the obstacles? Drug Alcohol Rev 2008;27:138–144]

Key words: barriers, consumer participation, drug treatment services, opinions, user involvement.

Introduction

In the last 20 years there has been an increased interest in, and commitment to, notions of rights and citizenship in public policy-making, in particular health policy [1,2]. Referred to as consumer participation, such policy-making seeks to include consumers of services in decision-making about service planning and delivery, and policy development. On an ideological level, it is thought to add legitimacy to service providers’ decisions about health service delivery, provide service consumers with a venue through which to demand accountability from service providers, and increase the sharing and valuing of consumer experiences and knowledge [1,3,4]. Consumer participation has been endorsed widely by governments, both in Australia and internationally [3,5,6], and has been particularly well developed in the field of mental health [4,7,8]. Evidence from case studies showed that consumer involvement can contribute to a range of changes, including increasing service accessibility, improving attitudes of organisations towards consumers and increasing the self-esteem of consumers [9].

While consumer participation in drug treatment settings has been institutionalised in policy and practice
internationally, in particular the United Kingdom [10], there has not been an equal level of formalisation in Australia. One part of the current study, reported in the companion paper [4], showed that a proportion of Australian services conducted some consumer participation practices. For instance, almost half of services conducted consumer councils or forums, and about two-thirds conducted consumer surveys [4]. However, there was a lack of policy directive and specific funding for these initiatives and they suffered significantly from a lack of communication between service providers and consumers [4]. The implementation of meaningful consumer participation policies and practices is highly dependent upon the opinions and beliefs of those involved. Social analyses reveal how the western biomedical mode of treatment is often predicated on a view of the ‘patient’ as pathological and needy [1,11,12]. Research from the mental health field reveals how both psychiatrists [13] and patients [14] take on views of the mental health patient as passive and lacking ability. This invalidation of personal agency is also evident in research from the drug treatment sector, where some treatment approaches position those seeking treatment as deficient, defective or ‘lacking’ [15]. This probably contributes to the lack of understanding between staff and clients that has been well documented in some drug treatment environments [16–18]. Consumers reported feeling that providers lacked understanding ‘because they have not experienced what “life is like on the street, what it’s like to be a junkie”, and how it feels to be “sick”’ [16, p. 506] and expressed the desire to sensitisise staff to their needs. Yet, despite consumers’ beliefs that staff do not understand their experiences, staff demonstrated their understanding of the complex needs of people seeking treatment, and concomitantly identified their own lack of education and resources to manage them effectively [19].

Given the way in which opinions and beliefs can shape the nature of treatment delivery, it is important to consider how these might impact on efforts to implement broadly a consumer participation initiative in Australian drug treatment services. Certainly, any endeavour to do so is predicated on the support and commitment of those most centrally involved. We developed and conducted the National Treatment Service Users (TSU) Project to describe the current opportunities for, and opinions about, consumer participation in Australian drug treatment services. The purpose of this paper is to describe service consumers’ and providers’ (1) beliefs about, and levels of commitment to consumer participation; and (2) perceived barriers to conducting or participating in consumer participation. The paper also includes an analysis determining whether beliefs of providers are different from those of consumers.

Method

Defining consumer participation

A definition for consumer participation was developed in consultation with the relevant literature to provide a typology through which interview questions were developed and data were interpreted (see Table 1 in the companion paper, this issue [4]). The typology recognises varying degrees of consumer involvement, from ‘low’-degree information provision and consultation to ‘high’-degree involvement such as shared decision-making between consumers and providers (following Arnstein’s 1969 ladder of citizen participation [20] and others [6,21,22]). In developing the typology, we drew upon written resources available within the Australian health service context [5,23–25] which provided examples of activities in which consumers could participate in service planning and delivery. The typology categorised each activity into ‘types of activities’, which were organised into degrees of participation ranging from ‘low’-level information provision and consultation, to ‘mid’-degree involvement of consumers in non decision-making activities, to ‘high’-degree shared decision-making.

<table>
<thead>
<tr>
<th>Agree or strongly agree that . . .</th>
<th>Service providers n = 64</th>
<th>Service consumers n = 179</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service quality would be improved if clients’ opinions about services were included</td>
<td>54 84.4</td>
<td>161 89.9</td>
</tr>
<tr>
<td>A client representative should be included on committees that decide or plan how services are run*</td>
<td>46 71.9</td>
<td>156 87.2</td>
</tr>
<tr>
<td>This service should hold open meetings to get clients’ views on how the service should be run</td>
<td>51 79.7</td>
<td>153 85.5</td>
</tr>
<tr>
<td>Clients are generally not interested in being involved in deciding or planning how services are run</td>
<td>20 31.3</td>
<td>73 40.8</td>
</tr>
<tr>
<td>Staff want clients to be involved in the way services and programmes are run**</td>
<td>41 64.1</td>
<td>53 29.6</td>
</tr>
</tbody>
</table>

*p < 0.01; **p < 0.001.
Data collection

The data collection method is described in detail in the companion paper [4]. Study respondents were service consumers and providers from pharmacotherapy, residential rehabilitation or residential detoxification services located in three Australian states: New South Wales, Victoria and Western Australia. Services were selected randomly from a recently compiled national list of drug and alcohol services [26]. Selected services were asked to nominate a “key informant” (usually a director, nurse unit manager or equivalent service manager) to answer policy and practice questions on behalf of the service. A list of 78 “key informants” were mailed invitations to complete an interview. Fourteen of the 78 selected services were chosen as locations from which to recruit consumers. All consumer participants were volunteers who responded to recruitment posters.

Data were collected using interviewer-administered structured questionnaires. Respondents were asked about their knowledge of and opinions about each of the consumer participation activities listed in the typology. Specific definitions for the activities listed in the typology are available in another study publication [27]. Questions ascertained opinions about each activity, whether respondents would be willing to support the conduct of (or participate in) activities, and their opinions about the barriers to conducting or participating in the activities. All questions were closed-ended except those regarding respondents’ opinions about perceived barriers. These questions were open-ended, with the interviewer asking, for example, “what do you see as the main barriers to attending a consumer council?”. The interviewer grouped the respondent’s answer into one of eight categories, which was confirmed with the respondent. Multiple-response options were presented in the form of a five-point Likert scale (definitely, probably, possibly, unlikely, no; strongly agree, agree, neither agree nor disagree, disagree, strongly disagree). Questionnaires were piloted prior to the main data collection to evaluate clarity of questions.

Interviews with service providers were conducted by telephone by one of the authors (MS). Interviews with consumers were conducted at the service they attended in face-to-face format by trained peer interviewers. Interviews were conducted by peers because this has been shown to facilitate recruitment and increase data quality because of a sense of shared norms and values [28]. Consumers were provided with AU$20 for their time and knowledge contributed to the study. Tests for differences in opinion between service consumers and providers were made using the $\chi^2$ test. Data were analysed using SPSS version 14.

The study received ethical approval from the human research ethics committees at the University of New South Wales and all relevant area and state ethical review boards.

Results

A total of 64 of the 78 invited service providers completed interviews [response rate = 82% (64/78)]; 179 consumers completed interviews. Detailed descriptions of the samples are available in the companion article [4]. Both consumers and providers agreed overwhelmingly that including consumers’ views about service provision would improve service quality (Table 1). Most consumers and providers agreed that this could be achieved by including consumer representatives on decision-making committees, although more consumers than providers were in favour of this approach (87.2% vs. 71.9%, $\chi^2 = 7.84$, 1 df, $p = 0.005$) (Table 1). Similarly, most providers and consumers agreed that service providers should hold open meetings (councils or forums) where consumers could express their views on service planning and provision (Table 1).

A considerable minority of consumers (40.8%, $n = 73$) and providers (31.3%, $n = 20$) felt that consumers would not be interested in being involved in service planning and provision (Table 1). Moreover, while most providers felt that staff of drug treatment services wanted consumers involved in service planning, significantly fewer consumers believed this (64.1% vs. 29.6%, $\chi^2 = 23.59$, 1 df, $p < 0.001$) (Table 1).

Service providers were asked their opinions about whether, in future, the staff and management at the service for which they work would be willing to conduct consumer participation activities. Similarly, consumers were asked whether, in future, they would be willing to take part in consumer participation activities. The majority of both consumers and providers felt that they (or the staff and management of their service) definitely or probably would be willing to take part in ‘low’- and ‘mid’-degree activities (Table 2). However, significantly fewer providers felt that their service would be willing to conduct ‘high’-degree activities, particularly those activities that involved consumers in decision-making matters relating directly to staff (training, performance appraisal and recruitment). Notably, more than half of both consumers (54.2%, $n = 97$) and providers (51.6%, $n = 33$) reported that they definitely or probably would be willing to have a consumer representative on decision-making committees (Table 2).

Service providers who expressed the view that the staff and management of the service for which they worked would be unwilling to support consumer involvement initiatives did so because they felt that many consumers lacked the necessary skills to participate, that staff would be reluctant to have consumers involved, or they viewed certain consumer involvement
activities as impractical, not valuable or inappropriate (Table 3). In comparison, consumers who reported that they would be unwilling to participate in consumer participation activities did so because they felt that it was not their place to be involved in service planning, they wanted to focus on their treatment, they viewed certain activities as not relevant to the type of service they used or they felt that they lacked skills and confidence (Table 4).

**Discussion**

Almost all consumers and providers believed in the principle of consumer participation (that consumers’ views should be included in service planning and delivery) and a large proportion reported that they would be willing to conduct or participate in consumer participation activities in future. This reveals the considerable support for consumer involvement in the planning and delivery of Australian drug treatment services from those that are or would be most centrally involved.

Some differences in opinion existed between providers and consumers, with fewer providers reporting that their service would be willing to include consumers in ‘high’-involvement activities in which consumers would share in decision-making that relates directly to staff (such as staff training, recruitment and performance appraisal). Providers reported that their reluctance related to concerns about the practicality of operationalising such activities, inadequacy of consumers’ skills and concerns about the appropriateness or value of having consumers involved in this way. Some of these reasons may derive from the way in which drug treatment services, like other mainstream health services, are structured by the western biomedical mode of treatment where ‘patients’ can be perceived as needy, deficient or ‘lacking’ because of their illness [11,12]. This is especially pertinent for users of drug treatment services who are known to have engaged in illicit drug use, a practice understood commonly to be socially deviant and in need of ‘fixing’ [15]. In relation to consumer participation, this means that clients of drug treatment services can be seen to lack the personal skills and agency necessary to participate meaningfully. Certainly, implementing such high-level consumer involvement could not take place without adequate training for both consumers and providers. Given appropriate training and experience, consumers would have the necessary skills to take part in shared decision-making processes. Moreover, providers’ concerns about the appropriateness of consumer involvement in staff-related decision making may diminish once they become more comfortable with consumers in this role. The mental health experience reveals that when consumers are established in high levels of involvement, such as providing education and training to health-care professionals, providers develop more positive views about consumers and become more favourable to including them [9,29]. Providers’ concerns might also relate to their fears of consumers’ encroaching upon what has been traditionally a professional sphere of practice. In mental health, this has been identified as an obstacle to strengthening consumer participation [30]. Despite the concerns of
some providers, a considerable number of other providers (between 18–40%) supported the notion of including consumers in decision-making that directly related to staff, and an even higher proportion expressed support for consumers on decision-making committees, revealing a significant foundation of support among Australian service providers for including consumers in high-degree activities.
While most consumers expressed the view that they would be willing to take part in consumer participation activities, those who reported unwillingness did so for reasons relating largely to beliefs about their own skills and role. Some reported feeling that it was not their place to be involved in shared decision-making with providers which suggests that, like providers, some consumers see themselves and other consumers as having particular roles within the treatment setting. Concerns about ‘appropriate’ roles may also reflect some consumers’ anxieties about having a ‘foot in both camps’, where consumers are seen to be in collusion with staff or would be involved in roles that gave them access to sensitive information about other consumers [30]. Thus, while shared decision-making with providers has clear advantages for consumers, it also brings with it tensions linked to consumers’ capacity to relate to other consumers and to concerns about confidentiality.

Another predominant reason for consumers’ unwillingness to become involved with consumer participation was a desire to focus upon treatment. This is a commonly reported pattern among consumers of other types of health services [31], where the desire for involvement is shown to be dependent upon the seriousness of illness, quality of relationship with providers and personal characteristics [31]. Clearly, a certain proportion of consumers will opt out of consumer involvement simply because they are not interested.

The study findings are highly robust due to the random sampling technique employed to select service providers. Consumers, however, as volunteers recruited from select services, may not be representative of other consumers at Australian drug treatment services. Moreover, some responses are based upon small numbers and should therefore be interpreted with caution. Finally, the definition or typology of consumer participation used in the study was developed specifically for the purpose of capturing a wide range of possibilities for consumer participation. While the examples it uses are practised in other areas of health service provision, it may not be consistent with or suitable for the needs and objectives of providers and consumers of drug treatment services.

In conclusion, the study showed that consumers and providers of Australian drug treatment services were strongly in favour of incorporating consumers’ views into the process of service planning and delivery. More research is necessary to explore how consumer participation might work in practice within drug treatment settings, and how policies can be constructed to ensure the sustainability and efficacy of consumer participation programmes. This needs to be conducted in a way that addresses the concerns and anxieties of all stakeholders. Taking forward any consumer participation initiative in drug treatment services will require training for both consumers and providers, particularly if they will be entering into a process of shared decision-making.

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References


