

❖ Chapter 2: Model and Definition of Consumer Participation

2.1 Model of Consumer Participation in Drug Treatment Services

This chapter outlines the framework adopted within the project for conceptualising and implementing consumer participation in drug treatment services. While there is a role for consumer participation at a number of levels (individual, local, state/territory and national), the focus of the TSU Project: Phases One and Two were in developing and implementing consumer participation at the level of drug treatment services and not in relation to individual treatment plans. The examples of consumer participation provided in this document are neither exhaustive nor prescriptive, but rather aim to provide a guide for developing and implementing consumer participation in drug treatment services.

Treatment service users are not a single identifiable group or community and therefore individual consumers and consumer groups will want different degrees and forms of consumer involvement (Greater London Authority, 2005). Likewise different drug treatment services will have different needs and capacities, and this will influence the types and levels of consumer participation that are appropriate for an individual service to conduct..

2.2 Definition of Consumer Participation

In much of the available literature, 'consumer participation' is broadly defined as 'the process of involving health consumers in decision-making about health service planning, policy development, setting priorities and quality issues in the delivery of health services' (Commonwealth Department of Health and Ageing, 1998).

In the general health context, consumer participation models typically incorporate varying degrees of involvement in service planning and delivery, ranging from the sharing of information and opinions about services to engaging in shared problem-solving and joint decision-making (National Resource Centre for Consumer Participation in Health (NRCCPH), 2002).

As part of the TSU Project: Phase One, a policy audit was conducted to review existing international, national and local policy frameworks to support the implementation of consumer participation in drug treatment settings. This policy audit revealed a number of policy frameworks at the international level, designed to encourage the active participation of consumers in both general health and drug treatment settings.

However, in the Australian context, despite a significant commitment at government and non-government levels to the principles and practice of consumer participation in general health settings,

there was virtually no evidence in the literature of policy frameworks to support consumer participation in the drug treatment context. Further, in the few examples of policies designed to specifically support the involvement of drug treatment consumers, there was little evidence to show how these policies have been implemented in practice (AIVL, 2008, p.43).

Given the strong evidence demonstrating the acceptance and value of consumer participation in general health settings, the TSU Project: Phase One utilised these existing mainstream models when developing the model of consumer participation used. In line with the literature, particular attention was given to developing a model that acknowledged the need for varying levels of consumer involvement in health service planning and delivery from low-level information exchange through to more active decision-making roles at the middle and higher levels respectively (NRCCPH, 2004). As the study was focused on consumer participation in drug treatment settings rather than the general health setting, some minor adaptations were made to the model to reflect examples of participation and involvement with direct relevance for drug treatment consumers.

Despite this, the findings from the TSU Project: Phase One highlighted a number of flaws in the definition and model of consumer participation adopted. In particular, some of the middle and higher level participation activities were found in practice to involve much lower degrees of active participation and/or decision-making than articulated in the model. For example, it was identified that incorporating principles of consumer participation into vision or mission statements or patient charters could, and frequently does, occur without meaningful involvement of service consumers. It was therefore identified that such activity may not involve consumers in decision-making roles at the levels necessary to qualify as high-level participation in accordance with the model (AIVL, 2008, p.45)

Further analysis of the data also identified that involving consumers in a number of the middle to higher level activities in the model, such as the development of information resources or on service committees, could also occur without empowering consumers to have a meaningful role in those processes. The importance of 'how' participation occurs rather than just 'whether' it occurs was the central issue highlighted, and this led to a rethinking of the definition and model of consumer participation adopted within the TSU Project: Phase Two.

The following model adopted in the TSU Project: Phase Two was developed with reference to available literature on consumer participation, findings from the TSU Project: Phase One (AIVL, 2008) and through consultation with the members of the Project Advisory Committee.

2.3 Definition of Consumer in the Drug Treatment Context

In the context of drug treatment services, consumers can be defined as treatment service users, including current and past users of services and people who are contemplating treatment (NSW Health, 2005).

2.4 Steps to Developing and Implementing Consumer Participation Activities in Drug Treatment Services

Drug treatment services need to establish their organisational philosophy before developing a new consumer participation initiative as it may be difficult to develop and implement consumer participation at the level of shared decision-making if the organisation does not already have a range of low-level

consumer participation activities in place, such as mechanisms for feedback, information sharing and recognition and commitment to consumer participation in a vision statement (Greater London Authority, 2005). Consumers and service providers will need to identify what, if any, forms of consumer participation already exist within the service. Identifying existing levels of consumer participation will assist the service in determining what level of consumer participation is most appropriate in the current environment. For example, if a drug treatment service wanted to involve consumers at the higher shared decision-making level the service needs to be able to answer 'yes' to these two questions:

- Does the organisation currently have mechanisms for keeping service users routinely informed about service developments?
- Does the organisation have mechanisms for getting feedback from service users?

Answering 'no' to these questions does not mean the service is not ready for consumer participation per se. However, it does mean the service will need to implement some strategies for sharing information and getting consumer feedback as a first step in the process of implementing and developing meaningful consumer participation. In addition to ensuring there are mechanisms for information and opinion sharing, treatment service users and providers should explore the following questions:

- In what ways would consumers like to participate in the service?
- What kind of skills will be required?
- What are the different levels and possibilities for participation within the service?
- How will the contributions of consumers in terms of time and expertise be supported?
- How will staff be encouraged and supported to engage with new practices of consumer participation?

Services will need to identify the skills already available as well as the necessary skills that need to be built. Training and skills development will be important for consumers, staff and management. For example, a consumer may need training around meeting procedures and business planning in order to participate effectively on a management committee. Staff and management may need training in approaches to communication and information sharing in order to build their capacity to work in a collaborative way with consumers (Greater London Authority, 2005).

2.5 Core Guiding Principles for Consumer Participation in Drug Treatment Services

Some of the fundamental principles that should underpin consumer participation in drug treatment services include:

- Service providers need to acknowledge the benefits of consumer participation and the right of consumers to have input into how services and programs are run;
- Consumers need to be engaged and involved from the beginning;
- Effective consumer participation requires leadership, funding and support; and
- The purpose of consumer participation programs/initiatives need to be clear from the outset.

Consumer participation initiatives should also:

- Involve a range of different consumers;
- Provide support and encouragement for consumers to participate, including providing practical assistance to consumers to enable them to participate fully;
- Allow the form and purposes of consumer participation to evolve over time;
- Ensure appropriate training is available for staff and consumers;
- Support consumers and providers in creating a non-threatening environment for both staff and consumers;
- Establish processes whereby both positive and negative feedback can be conveyed to staff;
- Establish a budget to fund consumer participation activities, including financial remuneration for consumer representatives. Remuneration has both a material and symbolic value;
- Develop mechanisms to ensure that consumer participation does not have adverse effects for the consumers involved;
- Establish and maintain the commitment and capacity for trust and mutual understanding between consumers and providers;
- Acknowledge that consumer participation might involve organisational change, including managers and staff being willing to relinquish decision-making power in order to achieve shared decision-making; and
- Evaluate, review and, where necessary, adapt to ensure consumer participation activities remain responsive to the needs of consumers.

The typology of consumer participation below was used in the TSU Project: Phase One. The diagram 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 ladder of citizen participation, 1969). The model provides examples of consumer activities associated with each degree of consumer 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 (AIVL, 2007).

Degree of consumer involvement	Type of participation	Example of Activity
HIGH	<i>Activities in which consumers share in decision-making</i>	<p>Consumer representatives involved in service planning committees: The service has had a consumer representative as a member of any committee that plans or makes decisions about services or programs.</p> <p>Consumer representatives attend staff meetings: The service has had a consumer representative regularly attend staff meetings.</p> <p>Consumer representative involved in staff recruitment: The service has had a consumer representative involved in the recruitment process for new staff at the service (e.g. a consumer representative contributed interview questions or was a member of an interview panel).</p> <p>Consumer representative involved in staff performance appraisal: The service has had a consumer representative involved in assessing staff job performance (e.g. consumer representatives meet with the nursing unit manager to give feedback on staff performance).</p>

Degree of consumer involvement	Type of participation	Example of Activity
MID	Activities in which consumers have non-decision-making roles	<p>Consumer involvement in resource development: Consumers involved in writing or reviewing written materials such as brochures, fact sheets, newsletters, magazines or educational resources.</p> <p>Consumers involved in staff training: Consumers involved in determining the content of in-service training that is directly relevant to consumers and their treatment.</p>
	Activities that promote and support consumer involvement	<p>Consumers are supported to conduct their own group activities: A service has ways to help consumers facilitate and run their own support groups (e.g. fitness groups, mums' and dads' groups) such as providing space, training or transport.</p> <p>Service displays user group publications — consumer forum: The service displays or makes available in other ways the publications of drug user organisations (e.g. NUAA, VIVAIDS, WASUA).</p>
LOW	Activities concerned with providing information to or receiving information from consumers	<p>Consumer councils: Committees or groups of consumers whose role it is to advise the service about how services and programs are run.</p> <p>Forums: Open meetings in which consumers can express their views about how services or programs are run.</p> <p>Surveys: Surveys that specifically ask consumers for their opinions about how programs and services could be improved.</p>
		<p>Suggestion box: The service provides a box where consumers can leave written comments regarding their views about how the service or programs are run and suggestions for changes and improvements.</p> <p>Complaints process: The service has put in place a process for consumers to register their complaints about the delivery of the service</p> <p>Produce resources for consumers that include information about service planning: The service has written or produced its own brochures, fact sheets, newsletters, magazines that specifically include information about changes to the policies and programs of the service.</p>
LOW	Consumer participation built in to the values and policies of the service	<p>Consumer participation incorporated into the vision or mission statement/ consumer charter of rights: A document is produced outlining client/patient rights, responsibilities and expected levels of service.</p>

These levels represent a range of opportunities for consumer participation. In practice, participation does not occur in all of these areas, in all services, or for all consumers all of the time. Opportunities to develop and implement consumer participation are greatly affected by context, environment and the attitudes of those who provide the services and the desires and needs of individual consumers (AIVL, 2007: pp. 23-24). Furthermore, while shared decision-making is a marker of high-level consumer participation it should be noted that information sharing and the inclusion of consumer participation in the values and policies of services (e.g. a consumer charter of rights), are not insignificant. In many cases these lower level activities will provide the basis for the development and implementation of other higher level forms of consumer participation over time.

2.6 Updated Literature Review on Consumer Participation

In addition to reviewing the definition and model of consumer participation applied, AIVL also reviewed the literature on consumer participation available since the publication of the TSU Project: Phase One Report. The following is a brief exploration of the available literature.

A number of papers explore consumer participation in mental health services. Even in that sector, where developments in consumer participation could be argued as most advanced, there are significant critiques aimed at policy and practice (Browne and Hemsley, 2008). For example, Stewart et al (2008) argue that mental health facilities have failed to implement consumer participation despite the lead provided by policy in this area. This supports the view of Happell and Roper (2007) that consumer participation needs to occur at different levels (advisory, consultation, collaboration and consumer led) to ensure that consumer participation is not tokenistic and, in turn, risks undermining consumer participation.

An area of importance identified in the literature is the influence of service staff on the success of consumer participation (Goodwin and Happell, 2007; Roper and Happell, 2007). While the literature identifies that the lack of a receptive culture, especially negative staff views of consumer participation, can produce significant barriers (Paterson et al, 2009), understanding the patterns and dynamics of staff attitudes (e.g. related to gender or professional experience) is important to better plan and support consumer participation (McCann et al, 2008). Besides the attitudinal culture in which consumer participation may be implemented, other aspects of the organisational context — such as bureaucratic processes, resources (human and material) and mechanisms to provide clear and timely feedback to consumers on consumer participation processes — have also been identified as important (Paterson et al, 2009).