

Model of Consumer Participation in Drug Treatment Services

The purpose of this document is to provide a framework 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, and National), the focus here is in developing and implementing consumer participation at the organisational level of drug treatment services and not in relation to individual treatment plans. The examples of consumer participation provided in this document are not exhaustive and nor are they intended to be prescriptive, but rather 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.

This model was developed with reference to available literature on consumer participation, findings from Treatment Service Users Project, Phase 1 and through consultation with the members of Treatment Service Users Project, Phase 2 Project Advisory Committee.

Definition of Consumer Participation

'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 Aged Care, 1998).

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, 2002).

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 (New South Wales Health, 2005:3).

Steps to Developing and Implementing Consumer Participation Activities in Drug treatment Services

Drug treatment services need to establish where the organisation is 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 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.

1. Does the organisation currently have mechanisms for keeping service users routinely informed about service developments?
2. 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 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 and the skills that it will be necessary to build.

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 in an effective way 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).

Core Guiding Principles for consumer participation in drug treatment services:

- 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.
- The purpose of consumer participation programs/initiatives need to be clear from the outset.

Consumer participation initiatives should:

- Involve a range of different consumers.
- Provide support and encouragement for consumers to participate; and
provide practical assistance to consumers to enable them to participate fully.
- The form and purposes of consumer participation need to be able to evolve over time
- There needs to be appropriate training available for staff and consumers
- Together consumers and providers need to create a non-threatening environment for both staff and consumers
- Processes need to be established whereby both positive and negative feedback can be conveyed to staff
- A budget needs to be established to fund consumer participation activities, including financial remuneration for consumer representatives. Remuneration has both a material and symbolic value.
- Mechanisms need to be developed to ensure that consumer participation does not have adverse effects for the consumers involved
- Commitment and capacity for trust and mutual understanding needs to be established and maintained
- Acknowledgment that consumer participation might involve organisational change, including managers and staff being willing to relinquish decision-making power in order to achieve shared of decision-making.
- Consumer participation activities should be evaluated, reviewed and where necessary adapted to ensure consumer participation activities remain responsive to the needs of consumers.

The typology of consumer participation below was used in the *Treatment Service Users Project Phase 1*. 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 (1969) ladder of citizen participation). 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 (Australian Injecting and Illicit Drug Users League (AIVL), 2007)

<p>LOW</p>	<p>Activities that promote and support consumer involvement</p>	<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>
<p>LOW</p>	<p>Activities concerned with providing information to or receiving information from consumers</p>	<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 held in which consumers could express their views about how services or programs are run.</p> <p>Surveys – surveys that specifically asked 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 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>

	<i>Consumer participation built in to values and policies of service</i>	Consumer participation incorporated into vision or mission statement; Consumer charter of rights – a document is produced outlining client/patient rights, responsibilities and expected levels of service.
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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. (Australian Injecting and Illicit Drug Users League (AIVL). 2007:23-24). 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, for example 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.

References:

Australian Injecting and Illicit Drug Users League (AIVL). 2007. *Treatment Service Users Project: Final Report*, Canberra Australia.

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