

## Executive Summary

This project was a peer-driven action research project which sought to implement a series of consumer participation demonstration projects in a variety of drug treatment settings in Australia.

The TSU Project: Phase Two follows the implementation of the TSU Project: Phase One research project in 2005-2007, which recommended a series of priority actions to support education and training in relation to consumer participation including:

- To develop a National Consumer Participation Demonstration Project to design, pilot and evaluate practical models of consumer participation in a range of drug treatment contexts;
- To provide training and education for drug treatment consumers to build skills, capacity and confidence in relation to consumer participation; and
- To provide training and education for service providers to build skills and capacity in relation to consumer participation (AIVL, 2008).

### Specific Objectives

The key objectives of the TSU Project: Phase Two were:

- To further refine and then apply the model of consumer participation in drug treatment services developed in the TSU Project: Phase One; and
- To conduct an independent evaluation of the suitability and impact of the expanded model within the five selected demonstration sites.

For consistency and to support comparisons across the two project phases, the five demonstration sites were selected from the same states as those who participated in the TSU Project: Phase One – New South Wales, Victoria and Western Australia. The demonstration projects included a range of metropolitan and regional, and government and non-government drug treatment services. The drug treatment approaches offered by the demonstration sites included:

- Pharmacotherapy;
- Inpatient Detoxification; and
- Residential Rehabilitation.

## Definition

'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).

The TSU Project: Phases One and Two used a model of consumer participation that was developed in consultation with the health consumer literature and from examples of consumer participation in other health services (including disability and mental health services). Consumer participation models generally feature varying degrees of involvement in service planning and delivery, with the lowest level being concerned with providing information to or receiving information from consumers. Middle-level consumer participation involves consumers in more active roles that encourage participation but do not involve decision-making. The highest degree of consumer involvement grants consumers decision-making roles in the planning and delivery of services.

Following the TSU Project: Phase One, a review and further refinement of the definition and model of consumer participation was adopted for the TSU Project: Phase Two. The main aim was to address a number of conceptual shortcomings identified in the TSU Project: Phase One model and to develop a definition and model of consumer participation that better reflected the complex and multi-layered nature of consumer engagement and stakeholder relationships in the drug treatment context. For a more detailed explanation of the expanded definition and model of consumer participation utilised in TSU Project: Phase Two, see Chapter 2 of this report.

## Method

The project included the following components:

- **State and territory forums and project promotion:** These included jurisdictional forums to present the findings from the TSU Project: Phase One and announce the commencement of the TSU Project: Phase Two, and the upcoming expressions of interest process for the demonstration projects. A promotional flyer and articles were also disseminated and published in relevant alcohol and other drugs (AOD) sector publications and online resources;
- **Expressions of interest process:** AOD treatment services in New South Wales, Victoria and Western Australia were invited to submit an 'Expressions of Interest' (EOI) to be selected as one of the demonstration project sites. See Chapter 3 and Appendix 3 for further information;
- **Selection of demonstration sites:** From the EOI process, eligible drug treatment services were invited to submit detailed project plans. Project plans submitted were considered by an assessment panel which selected the five successful demonstration sites. The site selection was confirmed by the Australian Government Department of Health and Ageing (DoHA). See Chapter 3 and Appendix 3 for further information;
- **Establishment and implementation of demonstration projects:** Project agreements, project planning, logframes, and reporting templates were finalised with each site. Basic orientation and training was provided as part of the projects for the consumer representatives and service providers involved. See Chapter 3 and Appendix 4 for further information and project documentation;

- **Evaluation and monitoring of demonstration projects:** This included an ethics approved, process-based evaluation involving a two-stage data collection process at baseline and toward the end of the agreed project timeframe using interviews with service providers and service users at each site. Ongoing project liaison and monitoring was also conducted with key staff at the demonstration sites and the local peer-based drug user organisation. Each project site was required to submit a final project report including project activities and outcomes and self-assessment of the impact and sustainability of the project. See Chapter 4 and 5 and Appendix 5, 6 and 7 for further information;
- **Development of the TSU Project: Phase Two Final Report:** The final project report was developed through a collaborative process involving AIVL, NCHSR and members of the Project Advisory Committee. See Chapter 6 and 7 for further information on project findings and recommendations.

## Key Findings

All projects aimed to recruit one or more consumers into consumer representative roles. Although the goals of the projects varied, all demonstration projects experienced problems in achieving their stated outcomes. A number of service and system level issues directly influenced the progress of the projects. Staff and management explanations for this situation included a belief that services are over-stretched and under-resourced. Services also consistently acknowledged that they had underestimated the amount of work involved in implementing the demonstration projects. In analysing the implementation and progress of demonstration projects, a number of inter-connected themes were apparent. Further, the importance and framing of some issues shifted significantly between baseline and evaluation data collection, indicating that the experience of conducting consumer participation projects was somewhat disconnected from initial expectations.

In outlining the findings below, AIVL wishes to acknowledge the complexities and difficulties that can be associated with conducting consumer participation projects in drug treatment settings from the service, staff and consumer perspectives. In presenting these findings, AIVL is seeking to learn from the demonstration projects with the aim of improving the experience of consumer participation for all involved.

### **Awareness, understanding and interest in consumer participation:**

- Levels of awareness and understanding of consumer participation exhibited among consumers across all five sites remained low throughout the project.
- A clear exception was apparent in those instances where consumer representative positions had been created as part of the demonstration project and the consumers fulfilling these roles were able to be interviewed.
- The data suggests that most consumers did value the concept of consumer participation in principle once it had been adequately explained to them.
- Although staff were generally more likely than consumers to be familiar with the term 'consumer participation' and broadly supportive of it, very few had any practical experience of conducting consumer participation activities in drug treatment settings.
- Aside from a minority of staff that remained consistently disinterested, opposition among staff appeared strongest when higher forms of consumer participation (such as staff recruitment or appraisals) were discussed.

### ***Stability:***

- The notion of 'stability', initially considered a 'positive' attribution of individuals at baseline, became a means to assess the suitability of services at evaluation. That is, what began as an assessment of the readiness of individuals to take on the responsibilities of consumer participation became, across the project, more of a concern about the capacity of services to run the project.

### ***Who is a consumer? Who can represent treatment service users?***

- Not unlike 'stability', the terms 'ex-user' and 'consumer' have become normalised within the taxonomy of drug and alcohol practice and policy. However, like 'stability', these terms are neither neutral nor fixed: their meaning and application varied across treatment settings and between speakers, from senior staff to consumers and across type of service.
- The fluidity (and power) of these terms need to be recognised in the context of this project where each carried considerable currency. These findings suggest that the model of consumer participation needs some further elaboration to account for the possible heterogeneity of treatment services users involved as consumers and consumer representatives.

### ***Expectations of the projects:***

- Expectations of the projects remained low to non-existent among consumers due to universally poor levels of awareness about both the projects themselves and the concept of consumer participation.
- The exception was among those consumers who had been recruited specifically into the roles of consumer representatives.
- Staff were mixed in their aspirations for the long-term benefits of consumer participation but a number of staff interviewed noted the positive impact of consumer participation on consumers in relation to gains in self-confidence and empowerment.

### ***Training and capacity building:***

- At baseline, staff across most services also believed that they did not require any specific training or education in regard to consumer participation. This led to services, as a whole, being somewhat underprepared in their planning, implementation and management of the demonstration projects.

### ***Power and risks***

- The existing culture in most drug treatment settings — including power dynamics between staff and consumers — can result in barriers to communication and trust, which in turn can affect the success of consumer participation in this context.
- There is a need for careful consideration and planning before services taken on the complexities incumbent in consumer participation.

## **Key Recommendations**

The key findings from the five consumer participation demonstration projects have been used to identify five priority areas to act as an overarching framework for the recommendations and actions that follow. Although the key findings have been drawn from the specific issues and outcomes identified by the staff

and consumers of the services involved in the demonstration projects, the key recommendations and actions take a broader 'services and systems' approach. In this regard, AIVL has not sought to make recommendations that would be of relevance and benefit to the services involved in the demonstration projects alone. Instead, the focus has been placed on the overarching themes and lessons learnt from the projects, and AIVL has attempted to interpret these in a way that supports the further development and sustainability of consumer participation in *all* drug treatment settings. It should also be noted that while the recommendations have been clustered as appropriate under one of the five priority areas, there is significant interconnectedness across the areas and recommendations — these linkages have been identified as appropriate. While some of the recommendations and associated actions specify the need for resourcing, it should be taken as read that all of the recommended actions will require appropriate resourcing if they are to be implemented.

### **Priority Action Area 1: Increasing awareness and understanding of consumer participation**

- **Training for staff of drug treatment services:**

***Recommendation:***

The development of a new consumer participation module within the Certificate IV in Alcohol and Other Drugs (AOD).

***Action:***

AIVL to approach the National Centre in Education and Training on Addiction (NCETA) and the Drug Strategy Branch, Australian Government Department of Health and Ageing (DoHA) to identify opportunities and pathways for the resourcing, development and implementation of the above module.

- **Training for consumers of drug treatment services:**

***Recommendation:***

The development of a national consumer participation in drug treatment training program and plan to support the delivery of consumer training at the local level.

***Actions:***

AIVL to approach the Drug Strategy Branch, DoHA to identify opportunities and pathways for the resourcing development and delivery of the above training program.

Should suitable resources be identified, the program would need to be developed and delivered in partnership with AIVL member organisations, other relevant advocacy groups and local consumer health forums.

- **Ongoing awareness raising in relation to consumer participation:**

***Recommendation:***

The development of a national communications strategy to address the lack of general awareness and understanding of both the concept and practice of consumer participation within the AOD sector and among drug treatment consumers.

***Actions:***

AIVL to seek placement of articles and editorial comment on the issue of consumer participation in key national AOD sector publications including, but not limited to, Of Substance, ANEX Bulletin, DANA Newsletter, etc.

AIVL and its member organisations to include articles and discussions on consumer participation and rights in drug user magazines, and provide articles for publications that target treatment consumers produced by other relevant organisations and services.

AIVL to seek a symposium or workshop at the Australasian Professional Society for Alcohol and Other Drugs (APSAD) Conference, which will focus on the definition of consumer participation in drug treatment settings, the value and benefits of consumer participation in this context, and practical strategies for developing and implementing consumer participation.

## **Priority Area 2: Making consumer participation ‘core business’ for drug treatment services**

- **Developing the policy framework to support consumer participation:**

### ***Recommendation:***

The development of a national advocacy strategy to promote the need for a policy framework at the national and state/territory levels to provide leadership and underpin support for consumer participation in drug treatment settings.

### ***Actions:***

AIVL to develop a brief consumer participation advocacy paper to be disseminated to, and as appropriate used to inform meetings with, the drug policy units of federal and state/territory governments and other government and non-government drug policy and consumer health bodies including the Inter-Governmental Committee on Drugs (IGCD), Australian National Council on Drugs (ANCD), Drug Policy Modelling Program (DPMP), national and state/territory consumer health forums, etc.

AIVL and its member organisations to advocate for the inclusion of principles and outcome indicators to support consumer participation in drug treatment settings in national and state/territory drug strategies and other relevant policy documents.

- **Funding and resourcing consumer participation in drug treatment settings:**

### ***Recommendation:***

Federal and state/territory governments to take a leadership role in supporting drug treatment services to incorporate consumer participation into service planning and delivery.

### ***Actions:***

Governments should incorporate minimum consumer participation requirements (based on the AIVL Model of Consumer Participation) into performance and funding agreements for drug treatment services.

*[\*\* It should be noted that responsibility for the above action will be with the federal or state/territory health departments, or a combination of the two, depending on the outcomes of national health system reforms currently underway. Based on the outcome of these reforms, this recommendation should be undertaken by the government entity(ies) with primary responsibility for funding government and non-government drug treatment services in the future.]*

Drug treatment services should be appropriately resourced to support and conduct consumer participation in drug treatment settings.

Should the above minimum requirements for consumer participation be incorporated into funding and performance agreements, AIVL and its member organisations should be resourced to provide expertise, partnership and support for drug treatment services in meeting such requirements.

AIVL will seek endorsement and support from the Chapter of Addictions Medicine, the Australasian Therapeutic Communities Association (ATCA), APSAD and other relevant bodies in relation to the above role and in being a recognised source of expertise and support on consumer participation in drug treatment settings.

AIVL will seek to work in partnership with other national and local consumer advocacy organisations as appropriate.

### **Priority Area 3: Developing a stronger theoretical basis for consumer participation in drug treatment settings**

- **Revising the AIVL definition and model of consumer participation in drug treatment settings:**

***Recommendation:***

To conduct a deeper analysis of the AIVL Definition and Model of Consumer Participation, including an exploration of definitions of 'who is a consumer', the concept of 'stability', 'who should represent consumers' and the significance of 'service type' for consumer participation.

***Actions:***

The NCHSR and AIVL to produce at least two peer-reviewed papers drawing on the findings and analysis of the TSU Project: Phase Two demonstration projects to further explore the definitions and issues identified above.

AIVL and the NCHSR to incorporate the ideas and thinking in the above peer-reviewed articles into the AIVL Definition and Model of Consumer Participation.

In addition to the above, AIVL and the NCHSR will incorporate a new section into the AIVL Definition and Model of Consumer Participation on 'who should represent treatment consumers' including:

- i. the concept of self-determination in relation to representation for different 'types' of treatment consumers;
- ii. appropriate consultative mechanisms to support the role of consumer representatives; and
- iii. the role of 'past treatment consumers' in the context of consumer participation in inpatient detoxification treatment settings and explore the potential value of other models of consumer participation in acute clinical care settings for application in the detoxification context.

## Priority Area 4: Acknowledging and understanding power and empowerment in the drug treatment context

- **Managing dynamics and relationships between staff and consumers:**

**Recommendation:**

To provide opportunities for staff and consumers to discuss how power and empowerment operates within the drug treatment context and develop positive strategies for acknowledging and managing these dynamics.

**Actions:**

AIVL to ensure issues of power and empowerment are addressed within the training for staff and consumers outlined in Priority Area 1.

Senior management of drug treatment services to encourage regular reviews of service systems and practices to remove barriers to consumer participation.

- **Managing dynamics and relationships between consumer representatives and other treatment consumers:**

**Recommendation:**

To empower consumers to take a leadership role in consumer participation activities in order to support the development of consultative consumer participation structures and processes.

**Actions:**

Drug treatment services should work with consumers to define the role of consumer representative positions and to develop consumer participation structures that support ongoing consultation between consumer representatives and other service consumers.

Consumer participation training for drug treatment consumers should be open to all treatment consumers, not simply consumer representatives.

## Priority Area 5: Engaging drug user organisations in consumer participation

**Recommendation:**

To support the greater involvement of drug user organisations in consumer participation in drug treatment settings.

**Actions:**

Training for services on working with drug user organisations should be included in funding and performance agreements for drug treatment services (*also see Priority Area 2 for further actions on funding and performance agreements*).

Drug user organisations should be appropriately supported and resourced to participate in consumer participation initiatives in drug treatment settings.