

❖ Chapter 1: Background

1.1 Introduction

The National Treatment Service Users (TSU) Project: Phase Two is a peer-driven action research project of the Australian Injecting and Illicit Drug Users League (AIVL) in collaboration with the National Centre in HIV Social Research (NCHSR). The Treatment Service Users (TSU) Project: Phase One Final Report 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, 2007).

To progress the above recommendations, AIVL submitted a proposal to the Drug Strategy Branch, Australian Government Department of Health and Ageing (DoHA) in late 2006 to conduct a two-year TSU Project: Phase Two with the primary aim of implementing the above recommendations from the TSU Project: Phase One. The proposed project model for TSU: Phase Two was to implement a series of five demonstration projects in a variety of drug treatment settings in order to:

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

In July 2007, AIVL in collaboration with the NCHSR commenced the TSU Project: Phase Two based on the above project plan with funding from the Drug Strategy Branch, DoHA. Originally, the TSU Project: Phase Two included a national workshop as the final project output to develop a national consensus statement on consumer participation in drug treatment settings. In late 2008 however, AIVL negotiated a variation to the funding agreement with DoHA to remove the national workshop and consensus statement from the project outcomes for Phase Two. The main reasons for these changes were a combination of unexpected delays to the establishment and implementation of the demonstration projects, and the lack of sufficient project resources to support the effective delivery of a national workshop.

Following the above agreement variations, the main agreed project outcome was a final project report documenting the process evaluation for the consumer participation demonstration projects. The draft project report was provided to the Drug Strategy Branch, DoHA in June 2009, with the final project report for the TSU Project: Phase Two negotiated for submission in April 2010 following the successful completion and evaluation of the five consumer participation demonstration projects.

1.2 Why was there a Need for a Phase Two of the TSU Project?

Prior to the research conducted in the TSU Project: Phase One, there was very little known about the reasons why consumers of drug treatment services have not been encouraged to participate in service planning and delivery to the same extent as other health consumers. The TSU Project: Phase One employed five methods of investigation to gain a better understanding of consumer participation in the Australian drug treatment context including:

- An audit of local, national and international policy frameworks in relation to consumer participation in health service planning and delivery;
- Interviews with service providers from 64 randomly selected drug treatment services in New South Wales, Victoria and Western Australia;
- Interviews with 179 service consumers selected from 14 of the above drug treatment services;
- Consultation with state and territory drug treatment consumer/drug user organisations; and
- A survey of key government, non-government and policy stakeholders.

The key findings from the above investigations included that:

- While areas such as mental health and disability have consumer participation policies, there are few examples of this in the drug treatment area in Australia.
- Consumer representative organisations emphasised a need for education of both consumers and providers and the facilitation of open and meaningful communication. They expressed beliefs that, if adequately resourced, consumer organisations are well-positioned to facilitate such education.
- Considerable communication gaps exist between consumers and providers regarding currently available consumer participation activities, with consumers knowing little about activities available at the services they attend. For example, while all consumers attended services that had a complaints process, only half (54.2%, n=97) knew about it.
- There was high support from both consumers and providers of drug treatment services with, for example, 71.9% (n=46) of providers and 70.4% (n=126) of consumers reporting that they 'definitely', 'probably' or 'possibly' would support having consumer representatives involved on decision-making committees. Providers were less supportive of 'high degree' activities in which consumer representatives would have decision-making roles in activities relating to staff (training, recruitment, performance appraisal).
- There are well-entrenched 'myths' about whether clients are interested in consumer participation with a strong belief among some service providers that consumers are not interested in taking part in consumer participation activities. Similarly, some consumers expressed the view that 'other consumers' were not interested in consumer participation. This contrasted sharply with reports from consumers themselves, many of whom said they would be willing to take part in consumer participation activities.

- There was a lack of awareness about the meanings and practices of consumer participation in the drug treatment sector, with many providers reporting that the main reason they had not conducted consumer participation activities in the past was because they had simply never thought about it. This suggested a need to raise awareness about the benefits of consumer participation and how it might work in practice.
- A number of resourcing and capacity issues were identified as obstacles to implementing consumer participation activities. Service providers reported inadequate funding and time restraints as reasons why they had not or would not be willing to support consumer participation at their services. Consumers reported beliefs that they lacked the necessary skills and confidence.
- The culture of some drug treatment services was identified, in various ways, as an obstacle to implementing consumer participation activities. A small number of study participants (including service providers, consumers, and other key stakeholders) expressed beliefs that it was not the appropriate role of consumers to have decision-making responsibility with regard to service planning and delivery, which may reflect the way that consumers' roles are often construed in terms of being passive or lacking (Treloar and Holt 2006). Moreover, the study findings identified that consumers had fears about participating in such decision-making activities, worrying that doing so might negatively impact their treatment or cause trouble for them in other ways.
- Other stakeholders (including representatives from key government and non-government organisations, and expert policy advisors) expressed overall support for consumer participation, identifying it as a priority issue for drug treatment services in Australia. Also, they generally agreed that any consumer participation initiative should be accompanied by specific, extra funding, and should include AIVL and/or its state/territory-based members as either leaders or key players in its implementation.
- Many services in Australia already conduct 'low degree' consumer participation activities that are concerned with providing information to or receiving information from consumers. For example, close to two-thirds (64.1%, n=41) of services reported conducting a survey within the previous 12 months that asked consumers specifically for their views on service planning and delivery.

The findings from the TSU: Phase One Final Report highlighted the need for further activity in relation to consumer participation in Australian drug treatment settings. While there was a high degree of support from both drug treatment service providers and service consumers for the concept of consumer participation, both groups had little understanding or experience of consumer participation in practice. There was also a clear need to improve communications between drug treatment service providers and service consumers to increase understanding and trust in relation to the purpose and benefits of consumer participation. In short, there was a need for a series of practice—based projects to demonstrate and evaluate whether consumer participation could work effectively in the drug treatment context.

1.3 Purpose and Scope

The main aim of the TSU Project: Phase Two was to independently evaluate the suitability and impact of an expanded model of consumer participation in a variety of drug treatment settings. The project involved the design, implementation and evaluation of five consumer participation demonstration projects in selected drug treatment services in New South Wales, Victoria and Western Australia. The selection of these states and territories ensured the demonstration sites for the TSU Project: Phase

Two were selected from the same jurisdictions as the participating sites that were drawn from the TSU Project: Phase One. Further information on the rationale for the participating jurisdictions and the selection process for the demonstration sites can be found in Chapter 3 of this report.

To ensure the independence of the evaluation and to protect the identity of the participating services and the confidentiality of the service consumers, the five demonstration project sites are not specifically identified in this report. The break-down by service type for the five demonstration projects included:

- **Pharmacotherapy services** including:
 - an inner-metropolitan, non-government service based on a primary health-care service model;
 - a large, metropolitan, government-operated service; and
 - a regional, non-government, community-based service model.
- **A detoxification service** based in an outer-metropolitan, government-operated, multi-disciplinary service model; and
- **A residential rehabilitation service** based on a therapeutic community model.

The project components included:

- **State and territory forums and project promotion:** This included jurisdictional forums attended by state/territory health departments, AOD services, community organisations, consumer groups and other stakeholders 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 was disseminated and articles were also published in relevant AOD sector publications, drug user magazines 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. The EOI process is explained in more detail in Chapter 3. Examples of the documentation from the EOI process are included at Appendix 3;
- **Selection of demonstration sites:** Based on the EOI process, eligible drug treatment services were invited to submit detailed project plans. Project plans submitted were considered by a three-person assessment panel which selected the five successful demonstration sites. The recommendations of the assessment panel were then confirmed by the DoHA. The selection process for demonstration project sites is explained in detail in Chapter 3. Examples of the documentation from the site selection process are included at Appendix 3;
- **Establishment and implementation of demonstration projects:** AIVL project staff worked with each selected demonstration site to finalise project agreements, complete planning for each consumer participation project and develop project logframes, and provided a project reporting template. Basic orientation and training was provided for the consumer representatives and service providers involved in the projects. The establishment and implementation of projects are explained in Chapter 3. Examples of the project agreements, project logframes and reporting template are at Appendix 4;
- **Evaluation and monitoring of demonstration projects:** Formal evaluation for the project included an ethics approved, process-based evaluation involving a two-stage data collection process at baseline and evaluation 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 and NCHSR project staff and the members of the Project Advisory Committee for the TSU Project: Phase Two. See Chapter 6 and 7 for further information on project findings and recommendations.

In addition to continuing to raise awareness of the important role of consumer participation in drug treatment settings, the combined purpose of both TSU Project Final Reports and the associated project documentation in the appendices, is to provide drug treatment services, consumer organisations and other interested stakeholders with information upon which to plan and implement future consumer participation projects. It is important to highlight that the lessons and experience documented through the evaluation process, the individual project reports and the project materials, taken together with the research findings from the TSU Project: Phase One, represent the only significant body of research and practice in the area of consumer participation in the drug treatment services in Australia to date.

1.4 Research Partnership

While the TSU Project is a project of the AIVL, a unique collaboration was formed at the commencement of the TSU Project: Phase One with the NCHSR which has been continued in the TSU Project: Phase Two.

Through this partnership, AIVL and the NCHSR have worked collaboratively on all aspects of the project including project and evaluation design, data collection and analysis, report writing and dissemination. The research partnership between AIVL and the NCHSR has produced benefits for both organisations, including:

- Capacity building for AIVL in relation to conducting peer-driven action research projects and process evaluations;
- Ensuring the right balance of consumer experience and research/evaluation expertise within the project;
- Strengthening collaboration between drug user organisations and national research centres;
- Expanding the scope of evaluative research being undertaken by the NCHSR; and
- Increasing the opportunities for future research and partnerships for both AIVL and the NCHSR.

1.5 Project Advisory Committee

AIVL recognises that the issues regarding consumer participation in drug treatment services are complex and highly sensitive for some stakeholders. To ensure the perspectives of all stakeholders were adequately represented, a multidisciplinary advisory committee was established to have direct input into the project and evaluation design, selection of the demonstration sites, evaluation tools, data interpretation, and drafting of the final recommendations and report. The membership of the committee

was carefully selected to ensure the inclusion of all perspectives and included:

- Two treatment service consumer representatives from different backgrounds and treatment experiences (in addition to the consumer expertise of the AIVL staff involved);
- Two service provider representatives;
- One representative from a relevant, recognised research institution;
- One representative from a relevant organisation with health consumer expertise;
- One representative on behalf of the AOD treatment sector;
- Two representatives from the Drug Strategy Branch, DoHA;
- One representative from the Australian National Council on Drugs (ANCD);
- One representative from the Inter-Governmental Committee on Drugs (IGCD);
- AIVL Executive Officer, AIVL Treatments and Policy Manager, and AIVL TSU Project Worker; and
- NCHSR project investigators.

The Project Advisory Committee (PAC) held two face-to-face meetings across the project in February 2008 and March 2010. A number of written updates were also provided to the PAC during the establishment, demonstration project and data analysis phases of the project.

A full list of members of the Project Advisory Committee is provided in Appendix 2.