⊹ Chapter 6: Discussion

6.1 Scope of the Study

In 2005 AIVL commenced a peer-driven research study in collaboration with NCHSR to gain a better understanding of consumer participation in drug treatment services in Australia. This study resulted in the publication of the TSU Project: Phase One Final Report in April 2008. The project recommended a series of priority actions to support education and training, policy development, funding and leadership in relation to consumer participation in drug treatment services (AIVL, 2008 and Byrant et al, 2008).

The TSU Project: Phase One was a ground-breaking project within the Australian AOD treatment sector (Patterson et al., 2009 and Ottman et al., 2009). As the first national research study into consumer participation in drug treatment settings in Australia, the project identified a number of key findings. These findings included a very high level of support for consumer participation among both consumers and service providers; a lack of resources, skills and capacity to implement consumer participation in practice; and a number of significant barriers to consumer participation caused primarily by the culture and power dynamics in drug treatment services.

Of particular note was the fact that although the vast majority of stakeholders indicated a strong level of support for consumer participation in the planning and delivery of drug treatment services, many stakeholders did not feel confident when it came to translating this 'theoretical' support into practice at the level of everyday service delivery. In this regard, the TSU Project: Phase One Report highlighted the need:

- To raise awareness of the benefits of consumer participation; and
- To provide advice to services on how to implement consumer participation in practice (AIVL, 2008, p.15)

As a strategy to actively support drug treatment services to implement consumer participation in practice, in mid-2007 AIVL commenced the TSU Project: Phase Two — once again in collaboration with NCHSR. The aim of this project was to conduct and fully evaluate five consumer participation demonstration projects in drug treatment services across Australia. The key objectives of the TSU Project: Phase Two were to:

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

By supporting and fully evaluating a series of consumer participation demonstration projects, the TSU Project: Phase Two was seeking to further explore some of the issues and barriers to consumer participation identified in the first phase of the project. In addition, the project aimed to document the potential benefits of involving consumers in drug treatment services and explore practical strategies for implementing effective consumer participation in treatment settings.

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.

Below we will discuss the key findings of the project evaluations. In Chapter 7 we will propose implications drawn from these findings in relation to recommendations for policy and practice.

6.2 Key Themes Identified in the Project Evaluations

6.2.1 Defining Consumer Participation

Based on the issues and inconsistencies identified with the definition and model applied in the TSU Project: Phase One (see Chapter 2), the definition and model of consumer participation in the TSU Project: Phase Two Project were modified to better articulate some of the complexities surrounding meaningful consumer participation in the drug treatment context. The revision process included:

- Providing more detail on some of the unique issues associated with consumer participation in drug treatment settings;

- The development of a set of guiding principles for consumer participation in drug treatment services; and

- A reworking of the TSU Model of Consumer Participation to include the qualitative aspects of meaningful engagement, such as ensuring that all mid- to high-level participation activities by definition would incorporate empowerment and genuine decision-making roles for consumers.

As in the TSU Project: Phase One, the TSU Project: Phase Two applied the above definition of consumer participation in all aspects of the project including site selection process and in evaluating the demonstration projects. The main point of difference between the two phases was redefining some activities within the levels of participation framework and adding a narrative section to the model to give more context and background to the definition. It should also be noted that there are many other definitions and models of consumer participation in the health context, and the definition and model utilised and the findings and outcomes of the TSU Project: Phase Two should be viewed within the context of this specific definition and model of consumer participation.

Following the evaluation of the TSU Project: Phase Two demonstration projects, some further issues were highlighted in relation to the definition and model of consumer participation. In particular, it

seems it may be necessary to further modify the model to incorporate a 'pre-consumer participation' stage whereby services are encouraged and supported to conduct establishment activities. Despite the fact that the TSU Project: Phase Two was targeted at services who were already undertaking lower level consumer participation activities, such as consultation and information sharing with consumers, the project evaluations did not confirm this level of consumer participation across most of the services involved. Indeed, the majority of services involved experienced significant barriers to undertaking their planned projects due to resourcing and planning difficulties and a general lack of opportunities to engage with consumers outside of the clinical environment.

As it currently stands, the definition and model of consumer participation adopted in the TSU Project: Phase Two commences the process of consumer involvement at the point of 'low level' information sharing between staff and consumers. However, the demonstration projects have highlighted the need for an additional level or stage of engagement that is focused on:

• Establishing communication and trust between staff and consumers;

• Raising basic levels of awareness and understanding of consumer participation;

• Increasing support for consumer participation and its potential value and benefits;

• Building skills in project planning and implementation; and

• Providing practical training for staff and consumers on consumer participation.

The outcomes from the demonstration projects (outlined in detail below) strongly indicate that there is still a need to build basic supporting frameworks for consumer participation within drug treatment services before meaningful engagement between staff and consumers can commence. The recommendations arising from this project emphasise this preliminary stage and outline actions at a number of levels to prepare the AOD service for greater consumer participation

6.2.2 Awareness and Understanding of Consumer Participation

Not unlike the TSU Project: Phase One study findings (AIVL, 2008, p.15), awareness of consumer participation was still generally low among both staff and consumers in the TSU Project: Phase Two. While staff in the TSU Project: Phase Two were somewhat more likely to have an understanding of 'consumer participation' very few had direct experience with consumer participation in practice. A number of services stated the existence, or planned implementation of, 'Consumer Charter of Rights' and 'Consumer Rights and Responsibilities' as being a legitimate form of consumer participation. However, in interviews with consumers most were not aware of the development of these policy frameworks.

Similar to this was the lack of consumer input into the development, design, implementation and assessment of the TSU demonstration projects. Despite the original aims of the demonstration projects, this lack of input meant that in practice most of the projects would be characterised as low-level consumer participation according to the model applied in the project (see Chapter 2). Similarly, many service staff were not involved in project processes including application, development, planning and implementation stages. While it is recognised that in some instances this will have occurred due to genuine staffing and resourcing limitations, staff in some services commented that processes tended to be done by a select few within the services, leaving other staff unaware of the projects. Similar issues to those identified above have also been discussed in the literature on barriers to consumer participation in other health settings (Cleary et al, 2006; Fortune et al., 2007; Hassett et al., 2007; Schauer et al., 2007).

Interviews with general service consumers, typically at both baseline and evaluation stages, demonstrated that many lacked an understanding and awareness of consumer participation in both theory and practice. In many instances 'consumer participation' and 'consumer representation' had to be explained to interviewees from the outset of interviews in order to continue. The consumers who did have an awareness and knowledge of consumer participation were, for the most part, those who had participated directly in the TSU Project: Phase Two demonstration projects, usually as consumer representatives. There also appeared to be a greater level of understanding among those consumer representatives that had participated in consumer participation training provided by the local peer-based drug user organisations.

In some cases, the interviews also created confusion for some consumers as it became apparent that service staff had told consumers the interviews were about the services they attended (and not the consumer participation demonstration project). For the most part, this meant that those consumer participants believed that service 'evaluation' — not evaluation of the demonstration projects — was the premise of the interview. This highlights the low profile that the demonstration projects had within some services and concomitantly points to the lack of knowledge and awareness about consumer participation processes in general.

Tending to fall into two categories, there were a few consumers who had a good awareness of both consumer participation and representation, and then a much larger proportion of service consumers who lacked clear knowledge of consumer participation. The significant gaps between the two groups of consumers indicate differences in how the demonstration projects were communicated to various consumers, and also suggest the need for capacity building and training to improve communication, confidence and trust among both staff and consumers. Service consumers' awareness and comprehension of consumer participation, as well as their willingness to participate in the process, appeared to correlate with both project progress and with the degree and type of training provided by services. In particular, consumer confidence in the project seemed to increase among those services where some training had been provided by the local drug user organisation either alone or together with another local consumer advocacy group.

This suggests that future consumer participation projects could significantly benefit from a number of key actions including the utilisation of training for consumers and staff from the early stages of project planning. Further, such training should be conducted with both staff and consumers with the help of local drug user organisations and other appropriate advocacy groups. This training should include understanding consumer participation and identifying its value and benefits, different approaches/models of consumer participation, recognising the knowledge and skills that consumers possess, and how services and consumers can work together to support consumer involvement.

6.2.3 Support for Consumer Participation

As with the findings from the TSU Project: Phase One, staff showed overall support for consumer participation, albeit at generally low levels (AIVL, 2008, p.14). When asked, the most common examples of consumer participation activities that staff were aware of included: client satisfaction surveys, consumer councils or committees, and suggestion boxes. Very few staff interviewed indicated support for consumer participation at higher levels, such as service planning committees and staff recruitment panels. Reluctance to endorse consumer participation was especially high when it involved decisions that could have potential impacts on staff (i.e. work appraisals, recruitment, etc). This is also consistent with the finding from the TSU Project: Phase One (AIVL, 2008, p.57).

A small number of staff directly involved with consumer participation projects stated that some staff were opposed to the concept of consumer participation, which in some cases caused problems with the demonstration projects. One staff member was quoted as saying he believed 'white-anting' took place as well as an overall reluctance to take on board the project aims. The influence of service staff on the success of consumer participation and the significant barriers that negative staff attitudes can have on consumer participation outcomes is well documented in the literature in relation to drug treatment and other areas of health service delivery (Patterson et al., 2009, Goodwin and Happell, 2007: Roper and Happell, 2007). At both the baseline and evaluation interviews a number of staff stated they felt 'disengaged' with the projects and were being asked to carry responsibilities for projects that had been developed without their input or approval. Given that there are existing concerns within some services about some staff being opposed to the inclusion of consumer participation activities, services should place a high priority on ensuring all staff are engaged appropriately in the planning and development phases of consumer participation projects (Patterson et al., 2009). Staff should also be provided with appropriate training and support in consumer participation and project planning.

While both the TSU Project: Phase One and Phase Two findings reflected a very low understanding of consumer participation among service consumers, once the concept and practice of consumer participation was explained, consumers generally expressed a high level of support for consumer participation (AIVL, 2008, p.86). Further, consumer projects conducted within drug user organisations have demonstrated that when educated about consumer participation in drug treatment services, consumers do develop the confidence to participate and have perspectives to offer that can lead to improvements in both policy and service delivery (Thompson, 2002). Given the absence of base-level knowledge of consumer participation among most consumers interviewed, the consumer interviewer explained consumer participation to consumers as being a form of advocacy, representation and participation in drug treatment. Some consumers misunderstood consumer participation to be more of an individualistic issue (i.e. what they could get for either the services or themselves, such as access to more take-away doses in pharmacotherapy programs and plasma televisions in residential rehabilitation services).

While improvements in service facilities are neither unrealistic nor unreasonable, consumer driven changes to clinical procedures and policies are more complex, particularly when governed by external authorities, such as area health services, government policy, etc. Nevertheless, this confusion highlights the importance of managing the expectations of consumers, particularly those expectations that are beyond the scope of the project, and that such management is an important part of consumer participation initiatives. The central importance of organisational context issues, including the full engagement of management and the establishment of mechanisms to manage the expectations of and provide timely feedback to consumers, has also been highlighted in a recent consumer involvement study in the United Kingdom drug system (Patterson et al., 2009).

A number of consumers interviewed did not see the value of either consumer participation or consumer representation. Instead, they maintained that the skills and experience required to undertake consumer participation and representation was more in the area of staff expertise and/or knowledge. This was due either to people thinking that they were not capable of making decisions regarding their own treatment (self-perceived deficits), or that staff were simply more capable of making these decisions on their behalf. While this could imply a good level of trust between those consumers and staff, it also highlights power and empowerment issues between staff and consumers in drug treatment settings.

It remains unclear whether such trust is a product of positive client-staff relations or, conversely, a reflection of high levels of disempowerment among consumers. It is acknowledged that some consumers do not wish to be involved in consumer participation, preferring instead to focus on their treatment and/ or because they have other priorities and commitments (AIVL, 2008, p.62). However, the issues raised here highlight the important role of staff in empowering consumers to further consider and/or take up participation opportunities. These issues and others relating to power and empowerment will be discussed in more detail in section 6.5 below.

While the issue was identified earlier in relation to staff awareness of consumer participation, evaluation interviews with staff indicated that another reason for lack of support for consumer participation may have been attributable to a lack of inclusion in the planning of demonstration projects. Some staff (both those with direct involvement in the projects and more general staff) stated that projects had been commenced without their knowledge. As a result, some expressed a lack of ownership over the projects and described feeling resentful due to having no inclusion in the beginning yet being expected to undertake much of the groundwork for the projects. Staffing and resourcing limitations notwithstanding, such problems could be avoided in the future by ensuring all staff are informed of potential projects at the planning stages.

As noted elsewhere in this and the previous chapter, successful consumer participation requires considerable effort and commitment from the service, staff and consumers. Without an adequate understanding and appreciation among key stakeholders of the value and benefits of consumer participation, it is unlikely that the requisite level of commitment to support a successful project will follow. For this reason, future projects should ultilise the experience and expertise of local drug user organisations to provide training to dispel negative misconceptions about consumer participation, including fear and misapprehension for both consumers and staff and to identify the positive impact that consumer participation can have on in the treatment context. Indeed, the National Treatment Agency in the United Kingdom has speculated that the unique expertise and experience of drug user groups may be central to achieving desired outcomes in relation to user involvement in drug treatment settings and, in any case, that users have the right to be involved (National Treatment Agency, 2002).

6.2.4 Valuing Consumer Participation

While staff in both the TSU Project: Phases One and Two interviews seemed to show support for consumer participation projects (AIVL, 2008, p.15), it is less clear whether there was an equivalent level of support for the 'value' of consumer participation. Some staff stated they believed it to be an essential need of their services (i.e. 'You can't call yourself a community service if you don't have community involvement'), however these opinions were not reflected across interviews with all staff. The evaluation data reflects a lack of a realistic appreciation of the level of work and the organisational infrastructure needed to implement their projects in line with the project plans submitted by services. Although some services appeared to commence and implement projects well in the early stages, in most cases there did not seem to be adequate contingency planning in relation to how they would respond to unforeseen problems and developments. For this reason, it was a combination of unrealistic expectations, inadequate project planning and support, and lack of contingency planning that resulted in the projects falling short of their planned outcomes. It remains arguable whether this lack of planning and, ultimately, progress represents a case of poor project planning or a more fundamental devaluing of consumer participation in this context. It is likely the answer to this question will differ across the services involved.

The above issues raise questions about the motivations of services in applying for the TSU Project demonstration project funding. Notwithstanding the low levels of funding available to support the demonstration projects, with the demonstration of consumer participation increasingly being included in service accreditation processes within the AOD sector, it is not unwarranted to ask whether services might apply for available funding for consumer participation projects with the main aim of meeting service accreditation requirements. This is particularly the case where meeting such requirements is increasingly linked to levels of funding and, therefore, staff and service opportunities. In this context it is not difficult to envisage a devaluing of genuine consumer participation policies and practices in favour of more perfunctory approach of 'ticking the boxes'.

Alternatively, the underperformance of the demonstration projects could also be interpreted as an issue of core versus non-core business. In this scenario any 'additional project' would suffer from a lack of attention and commitment because it was not designated as 'core' business and incorporated into position descriptions, business plans, etc. Once again, the level of funding AIVL was able to make available for the demonstration projects may have contributed to the relative deprioritising of the projects. The idea of consumer participation not being 'core' business was certainly raised in the evaluations by staff and some consumers.

Regardless of whether the demonstration projects seemed to suffer due to ulterior motives related to accreditation standards or an undervaluing or deprioritising of consumer participation, or some of both, the pathway to addressing the problem of project underperformance is essentially the same. Although the reasons why the projects did not achieve their full outcomes is very important (particularly the unique reasons for each service), it is also reasonable to state that the full value of consumer participation will not be recognised until it becomes a 'normal' or required practice within each service. In this regard, it is recommended that the core requirements and policy frameworks for drug treatment services are amended to support and embed active consumer participation at all levels of organisation. This process could start to foster a higher level of interest and participation from staff and perhaps counter negative staff attitudes. It could also serve as a precipitator for making more service resources available for consumer participation activities.

6.2.5 Who is a Consumer?

The determination of 'who is a consumer?' in relation to consumer participation is not an issue that can be surmised easily or universally agreed upon. While in lay terms it can be defined as someone who buys and/or consumes merchandise or services, in treatment settings there are many varied opinions as to where this begins and ends, and also what characteristics make a 'good' consumer representative. The study findings in both the TSU Project: Phases One and Two reflect that different treatment settings can influence a variety of beliefs among both staff and consumers in relation to 'who is a consumer'. In addition to this, there were also differences in opinions in relation to what constitutes a 'current user' and an 'ex-user', what roles past consumers can have in consumer participation, what constitutes 'stability' for consumers (often stated as a 'required' characteristic for being a consumer participant) and, finally, who should represent consumers in general. Each of these complex and multifaceted issues will be explored in turn below in the context of the findings of the demonstration projects.

6.2.6 Current Users and Ex-Users

Much like defining who is a consumer in the context of consumer participation, the question of what constitutes a 'current user' and an 'ex-user' varied greatly among and across those interviewed at

baseline and evaluation. Far from viewing this as a single continuum where a person is a 'current' or 'active' drug user then progresses to abstinence thereby becoming an 'ex-user', the concept of the 'current user' and the 'ex-user' had very different meanings for both staff and consumers across the different types of treatment services. For those in residential rehabilitation and detoxification facilities, 'ex-users' appeared to be those who had engaged in treatment and remained abstinent from drug use. Coupled with this sentiment was the opinion that ex-use (or abstinence) must be followed by a significant amount of time free from drug use. While acceptable 'times' of abstinence were not stated specifically by either staff or consumers, it seemed necessary for one to be 'drug free' for a significant period of time. Among certain service types and some staff and consumers, the presence of 'stability' in one's life was often indicated as being a good sign that someone was 'drug free'. The concept of stability and how it was perceived by both consumers and staff is discussed in detail in 6.4 below.

Within pharmacotherapy settings, distinguishing between 'current' and 'ex-users' was not as clear-cut as within residential rehabilitation services nor was it considered a necessary prerequisite in choosing 'good' consumer participants. Moreover, consumers held the view that people still on treatment (i.e. pharmacotherapies such as buprenorphine and methadone) were better suited to being consumer participants than those who were not. The main reason provided for this view was that people not currently in treatment were too far removed from the drug-using community and thus unable to accurately relate to those in current treatment. It is also worth noting that many consumers in these settings were of the opinion that staff who were 'ex-users' were much more effective in relating to service users needs than 'non-users' who they believed had gained their knowledge primarily through 'textbooks' as opposed to lived experiences.

While the question of when a current user becomes an ex-user remains a murky one, it is undoubtedly one of the most contested issues in relation to effective consumer representation. It may be that there is a call for different 'types' of consumer participants within different treatment settings. For example, people on pharmacotherapies representing others in the pharmacotherapy setting, and current and/or past consumers of residential rehabilitation and detoxification services representing those within their relevant settings.

Finally, a related issue that emerged during the baseline and evaluation interviews was that of the role of 'ex-user' staff member. As identified in the findings, a staff member at one service claimed that at least 70% of their current staff were ex-users. While this issue potentially raises questions about staff identity and allegiances, particularly on more 'sensitive' issues of service policy and practice, the more important issues in relation to consumer participation are those of relative role and power. While staff members in treatment services with personal drug use and/or treatment histories undoubtedly bring a different experience than staff without this background, it does not necessarily follow that staff with direct personal experiences can simply 'replace' the need for input from current treatment consumers. There are a number of reasons for this, including the fact that one could be a staff member who is an ex-user who has never been in treatment or in that type of treatment and therefore have little more to offer than other non-using staff. Perhaps more importantly, however, is the fact that being a staff member (even one with a 'past') is not the same as being a consumer of that or any other treatment service. Staff are appointed in a professional capacity. Their role and power within the service is very different to that of a current consumer. The other issue that is very important in relation to 'ex-users', particularly those on staff, is that of 'community connectedness', which is explored below in relation to 'past consumers'.

6.2.7 The Role of Past Consumers

In both the baseline and evaluation interviews for the TSU Project: Phase Two, the role of past consumers in treatment services was acknowledged as being important for consumer participation. Much like the issues 'who is a consumer?' and 'users versus ex-users', there were mixed opinions on what the role of past consumers should be, and who was more appropriate for consumer participation roles. Staff at both baseline and evaluation were reasonably consistent in their belief that, while past consumers should definitely have a role in consumer participation, the level and extent of this role was limited to what would be classed as 'low-level' consumer participation, that is non-decision making roles. Limiting the role of past consumers is also consistent with the view put by many staff in both baseline and evaluation interviews that it was not the role of consumers (presumably past or current, although this was not specified) to have significant input into service planning and delivery or general organisational decisions; least of all those processes that directly affect staff, such as staff appraisals.

Opinions on the role of consumers also differed greatly among consumers interviewed, though more so across different services and individuals, rather than over time (thoughts were fairly consistent across both baseline and evaluation interviews). Again comparable to the responses in the TSU Project: Phase One, some consumers were uncomfortable or reluctant with the idea of consumers having a role in their own treatment, believing that this could have negative repercussions for them with their service provision or that they were not knowledgeable enough or confident to represent consumers effectively (AIVL, 2008, p.62). Others held the belief that consumers should be entitled to have input into their treatment and were the most suited to 'knowing' what other consumers wanted and/or needed.

Although there could be disadvantages to involving past consumers in consumer representative roles, particularly the potential for them to be 'out of touch' with the issues or what is happening in services at that time, the advantage is that it could be a way to address the very real concern raised by consumers above about negative repercussions for their treatment. If you are not currently a consumer but someone with past consumer experience you may have a good understanding of the issues facing consumers without having anything 'to lose' by having to raise 'difficult' issues or criticisms of the service.

In many ways, whether this is a viable option or not will depend on the level of 'community connectedness' for each past consumer. If a past consumer continues to be part of local drug user and/or consumer treatment networks or has personal connections with people on treatment programs, their understanding of and capacity to represent the issues and needs of current consumers could be much greater. Alternatively, being removed from direct experience with treatment services over a long period of time or having only ever been involved in one type of treatment service may mean the individual is unable to adequately represent consumer issues regardless of whether they have ongoing connections or not.

The complexities of this issue are also reflected in the consumer data. In many instances, consumers at both baseline and evaluation held similar views about the importance of including past consumers in consumer participation. Consumers of residential rehabilitation services at baseline and evaluation were more likely to believe that past consumers were more suited to consumer participation due to their 'stability'(i.e. further removed from 'chaotic' lifestyles and more able to commit to involvement at this level). Likewise, consumers from detoxification facilities also believed 'stability' or being 'clean' (complete abstinence from drugs) was important for consumer participation — thus the emphasis of past consumers being more suitable.

Those from pharmacotherapy settings were a lot less likely to hold the belief that a consumer participant should be a past consumer; though some consumers did not seem completely opposed to this concept. There was a general support for keeping people within the service engaged (which implied current users and/or people on pharmacotherapies) in consumer participation as it was stated that people who were on treatment would have more of a personal and immediate understanding of other consumers' experience in treatment. For some in this setting 'past consumers' literally meant 'past' — that is, no longer a consumer and therefore not representative of current consumers and related issues.

While the comments above illustrate wide-ranging views among current treatment consumers on the role of consumer representatives and what constitutes consumer representation, it is clear that many believed 'current treatment consumers' had a valued and important role in consumer participation. The issue of 'stability' was raised either directly or implied through other terminology (such as the need to be 'able to fully commit to consumer participation'). To some extent, this implied that many people believed or assumed 'stability' to be a continuum on which consumers consistently 'improved' (i.e. more time passed equalled more stability). Much like 'who is a consumer?', the issues surrounding 'stability' are neither easily surmised nor clear-cut; this is also discussed in more detail throughout the following sections.

The central issue proposed here is that more than stability and ex-use or current use, 'connectivity' with the community represented should be the principal measurement or guidance that determines a person's suitability for consumer representation and participation. Connectedness to community or a person's acceptance within drug user/treatment consumer networks results in an awareness of the current and relevant issues and experiences for current treatment consumers. If people are too far removed from users and treatment consumer networks then they are not sufficiently 'connected' to represent these issues for consumers. This is an issue repeatedly discussed within the peer education literature — that the acceptance by the target group is the key characteristic of a peer (AIVL, 2006). The literature in relation to hepatitis C peer education and treatment support also highlights this concept with peers stating that their most trusted and credible source of information and support is through other peers and drug user organisations (Norman, J et al., 2008 and Richmond, J. 2010).

In the final analysis, it will be important to carefully weigh the pros and cons of considering the use of past consumers for representative roles as this could easily act as just another barrier to current consumers developing the confidence to represent and address their own issues and needs. Ultimately, if current consumers are expressing concerns about repercussions or their own capacities to take on representative roles, perhaps it is better for services to tackle the underlying causes of these reservations rather than seeking to avoid them by using non-consumers (such as family members or carers — no matter how well meaning), past consumers or even staff with past using or treatment experiences to undertake the role. In the end, the focus must be on what best meets the needs of current service consumers not whatever is easiest for the service and its staff.

6.2.8 Who Should Represent Consumers?

Although it was raised somewhat unexpectedly, the issue of a small minority of consumers that people in treatment for alcohol use were somehow a better-quality person or more suitable for undertaking consumer representative roles than those seeking treatment for illicit drug use issues is a matter that warrants further discussion. Setting aside the merits or otherwise of the views expressed, the issue highlighted by these comments is the importance of considering relationships between consumers. In planning for and conducting consumer participation, it is not just about the relationships between

staff and consumers or about the nature and structure of the service. Complex relationships among consumers within services and across services are also central to making consumer participation work.

The wide-ranging views expressed by both staff and consumers on critical issues such as identifying who has the 'right' to represent consumers, who would make the 'best' consumer representatives and inter-related issues of power and trust indicate the centrality and importance of diversity to consumer participation in this setting. In particular it indicates a need to ensure a 'valuing' of diversity and of the associated principles of self-determination and community connectedness. Attitudes and assumptions of staff in relation to both consumers and other staff, and the attitudes and assumptions of consumers towards both staff and other consumers, highlight a need to provide training and education to challenge negative stereotypes and dispel myths and poor attitudes before meaningful consumer participation can even begin.

However, the data shows that many of these attitudes and values are deeply held and are unlikely to be changed through training and education alone. Indeed, other areas of research have shown that changing entrenched negative attitudes, particularly those of health care professionals towards people who use or have used illicit drugs, needs more than training and education to achieve genuine change (Treloar, C and Hopwood, M., 2004). Consumer participation in the general health context has also shown that it is the creation of opportunities for staff and consumers to engage outside of the usual clinical environment — an environment that has often reinforced rather than challenged poor attitudes — that, over time, can help both staff and consumers to understand each other's values and skills (Alexander and Hicks, 1998). While we are not aware of research into strategies for changing negative perceptions and stereotypes held by consumers about other consumers, it is reasonable to assume that opportunities for further engagement and consultation could also assist consumers to better understand and appreciate each other's contributions.

Addressing a broad diversity of views in relation to 'who' should represent treatment consumers will also require the development of fair processes to allow different groups of consumers to form their own networks and identify representatives that they believe best represent their issues and needs. This includes ensuring that current service consumers are part of developing any criteria for consumer representative positions and/or proposals for consumer participation activities. This allows for self-determination and for consumers to be part of the defining processes by which their needs and issues will be addressed. There will be a need for flexibility, to refine approaches or make mistakes and start again. Opening genuine communication between staff and consumers about the characteristics of an effective consumer representative allows for the exploration of issues that, for the most part, did not seem to be discussed in the demonstration projects.

This apparent lack of focus on some of the more formal aspects of consumer representation and participation within the projects has resulted in a situation where this report is unable to do more than raise a range of extremely important yet highly complex and inter-related issues in relation to consumer identity and representation in drug treatment settings. For example, the distinctions raised above in relation to alcohol treatment consumers versus consumers of illicit drug treatment services raises the possibility of consumers being inappropriately represented 'within' a single service or 'across' services. This could occur by people who use or have used different drugs to some or even most of the consumers in a particular service or cluster of services being selected to represent 'all' consumers, and perhaps lacking the requisite knowledge and/or experiences to understand and articulate what others want/ need for their own treatment.

The data also raises the possibility of current consumers being represented by people who are possibly too far removed from (or not at all connected to) the issues of relevance (i.e. non-drug users or ex-drug users representing current treatment consumers). Finally, the issue of staff with past using or treatment experience being a 'substitute' for current consumer representatives was also raised by the data. It is unfortunate that the important issues raised by the concept of 'staff consumer representatives' — including that of self-identity, role definition, professional boundaries and power ¬— were not sufficiently explored by any of the projects. It is arguable that these issues were beyond the scope of this project but, equally, the fact that they were raised within the context of projects on consumer participation does potentially bring them within the project's scope.

So what then can be said about the above issues and what they mean for 'appropriate' consumer representation? For the reasons already outlined above, 'connectedness' to one's network or community is probably the most powerful asset a consumer representative can possess. Community connectedness is also likely to be the most effective way to address the complex representative issues raised across the evaluation data. Taking this approach avoids getting caught in either circular or dead-end discussions about who is a consumer, when does someone become an ex-user, can past consumers represent current consumers, does drug of choice matter, etc. Ultimately, by reviewing one's connectedness to people currently using and in drug treatment, a consumer representative can assess and, importantly, be assessed as to whether they can effectively represent the issues and needs of a particular group of treatment consumers. The necessity of this two-step process of not only self-identifying as a peer or consumer but being identified and accepted by others as their peer or fellow consumer is well documented in the available literature (AIVL, 2006). It also goes some way towards addressing many of the issues and questions outlined above from the data.

Treatment consumers have the right to be represented by people who have a genuine interest in and commitment to consumer participation and the skills needed to represent and advocate for the relevant consumers. However, this can only occur in practice when consumers are genuinely supported to implement or be part of fair processes that are inclusive, consultative and designed to meet the actual rather than perceived issues and needs of treatment consumers. This includes supporting consumers to drive processes to elect consumer representatives by seeking the support of local drug user organisations in training and ensuring processes to allow consumer representatives to consult with other service consumers. It also means ensuring that consumers have genuine input into the decisions made and activities undertaken. Consumer representatives identified, selected, trained, supported and managed by staff and services alone may result in a form of consumer participation that is considered easier for the staff and service concerned, but it is unlikely to result in meaningful consumer participation or in an 'appropriate' consumer representative.

6.3 Type of Treatment Service

The type of treatment service and its influence or impact ran through almost every issue and theme in regards to consumer participation. Among the different service types there were very different ideas on who consumers are and should be from both the consumer and staff perspective. Some of the reasons for this situation related to the different models of care, treatment environments and service philosophies among each of the services. For example, within residential rehabilitation, abstinence was the end ambition or goal. Similarly, in detoxification facilities, short-term medication was offered with

abstinence presumed afterwards. In pharmacotherapy settings, however, the underlying premise of treatment is one of harm reduction that does not necessarily assume or exclude total cessation of or abstinence from illicit/licit drug use.

6.3.1 Pharmacotherapy Services

At baseline and evaluation the pharmacotherapy services were the ones that had taken steps to engage drug user organisations in the training for their demonstration projects. It appeared they were more accepting of the role of drug user organisations, in general, and the principles underpinning them. This apparent acceptance most likely related to the fact that these services and the drug user organisations shared a support for the philosophy and practice of harm reduction; unlike other services where promoting harm reduction (and therefore the potential of continued drug use — illicit or licit) would conflict with organisation's core values. It is also the case that these services had some degree of existing relationship with their local drug user organisation, which is likely to have created a platform upon which to base involvement in the consumer participation demonstration projects.

Overall, the consumer participation projects in pharmacotherapy services involved consumers to a greater degree and were also more supportive of consumer participation in general. Consumers interviewed from these services generally exhibited a higher knowledge of consumer participation, more direct involvement in service projects, and showed confidence (more so at baseline than at evaluation) in their ability to represent other consumers within the service. The findings also suggest that there was a direct correlation between the degree of project progress and training provided by the local drug user organisations.

In some instances, both baseline and evaluation interviewees stated that they were content to allow staff to speak and/or act on their behalf as they believed that staff not only knew what was best for them but had their best interests at heart and were far more likely than consumers to do an effective job of representing consumer needs and issues. While this apparent level of trust could on the one hand be a sign of the quality of the relationship between staff and consumers, on the other it could be a sign of almost total consumer disempowerment or at least resignation. It was not clear through interviews how this situation had been allowed to develop. For example, it was unclear whether it had come about through 'empathetic' staff actively speaking on behalf of consumers, thereby removing the need for consumers to speak or take action on their own behalf, or whether consumers had actively given up their right to speak or take action — or a combination of both. It is also possible that a situation like this could develop if staff did not have the confidence in consumers to represent themselves effectively, were concerned about consumer 'vulnerability' and/or if staff did not believe consumers would be interested in taking part in consumer participation activities — a view also supported in the findings of the TSU Project: Phase One (AIVL, 2008, p. 14).

Whatever circumstances have given rise to this situation, it is one that needs to be redressed in the best interests of both consumers and staff. The very nature of pharmacotherapy services can militate against the empowerment of consumers and towards the formation of highly dependent relationships. There is strong evidence that many pharmacotherapy consumers will experience multiple treatment episodes across many years (ANCD, 2009). In this regard, it is important that staff do not enable or facilitate (even inadvertently) consumers taking a passive role in relation to advocating for and representing their treatment needs and issues. If, as the evidence suggests, consumers are likely to be spending long periods of time in treatment and moving between treatment services, they need to be supported to develop the skills and confidence to respond effectively to a variety of treatment contexts. Regardless

of whether consumers express the view that they are happy with the service and do not need to have avenues to represent their needs and issues, staff should initiate steps to empower consumers and support them to make their own independent decisions and develop their confidence to represent themselves effectively.

As mentioned above, pharmacotherapy service settings by their very nature have consumers who are highly dependent on the medication they are prescribed. While consumers may have a willingness to engage in consumer participation, some, indeed many, may be acutely aware of risking losing access to take-away doses and even their place in a treatment program itself by saying and/or doing something that is perceived by staff or the service as 'wrong' (i.e. being critical of services or staff or being labelled as a 'trouble-maker'). Whether this is a real or perceived fear of consumers, it is still a fear that may inhibit consumer involvement. Such fears were also confirmed in the responses from consumers in the TSU Project: Phase One (AIVL, 2008, pp.54-56). However, there are many practical steps that can be taken by staff and services to address such concerns or at least to reduce the likelihood of them resulting in consumers choosing not to participate. For example, providing opportunities for consumer participation away from clinical interactions (such as a separate room for consumers to meet privately) will support more confidentiality and allow interaction to take place away from the immediate clinical environment.

6.3.2 Residential Rehabilitation Services

Some staff interviewed from residential rehabilitation services believed that the environment and setting of their services were by nature conducive to consumer participation. The shared living environment and duties (such as cleaning and cooking, etc.) meant that consumers participated in service programs and had input and contribution into how they 'lived'. Many staff argued that the very nature of therapeutic community-based residential rehabilitation fosters almost constant consumer participation. While it is possible to identify processes and activities to support this case, it is also possible to point to factors that might question whether it is appropriate to label all activities within the residential rehabilitation context 'consumer participation'. This theme was also explored in the TSU Project: Phase One where describing ongoing involvement in practical operational issues (such as work schedules, menu planning and cleaning) as 'consumer participation' was questioned. While it was recognised that such activity could be useful in building a foundation for future consumer participation, the absence of 'choice' (in that consumer involvement in practical operational tasks is not optional but a compulsory part of one's therapy) led to a questioning of whether certain activities should really be characterised as consumer participation in their own right.

At both baseline and evaluation the residential rehabilitation service was less likely to engage the local drug user organisations in their consumer participation project than the pharmacotherapy projects. Despite the fact that AIVL directly facilitated connections between the service and the local drug user organisation, neither the service nor the drug user organisation actively pursued this relationship beyond these initial meetings. Further work needs to be done to better understand why neither party attempted to continue the dialogue and whether this related to a lack of resourcing, philosophical differences or other factors. The evaluation of the demonstration projects has shown the important value of involving drug user organisations in consumer participation initiatives and resolving potential barriers to collaboration.

In the residential rehabilitation project, communication between staff members about the project appeared to breakdown with some staff not knowing what 'project' had been done, or who was

managing the project. Likewise, communication between staff and consumers was also limited. Many consumers were not aware that the demonstration project was being run, with most consumers stating in interviews that they were told they were participating in a 'service evaluation' rather than an evaluation of the consumer participation demonstration project. At baseline and evaluation, consumers in the residential rehabilitation site were also less likely than pharmacotherapy consumers to believe they were capable or suitable to be consumer representatives. Many stated they would prefer staff to make these decisions or, at the very least, have long-term residents (people who had been there longer) as consumer representatives. While there were some opportunities for 'senior' or long-term residents to participate in certain aspects of service decision-making and planning, similar opportunities for new or younger residents were not particularly evident.

As identified in relation to the pharmacotherapy services above, regardless of whether consumers express that they are happy with a service and do not need to have avenues to represent their needs and issues, it is important that staff initiate steps to empower consumers. This should include supporting consumers to make their own independent decisions, and to develop their confidence to represent themselves effectively. The fact that the majority of consumers interviewed at evaluation were not aware of the consumer participation demonstration project serves to underline the urgency of this issue. In therapeutic community-based residential rehabilitation services, in particular, there also needs to be discussion about the nature of consumer participation in this environment and whether it can really be claimed, as it currently is, that compulsory participation by residents in the 'day-to-day running' of the service (such as cooking, cleaning, etc.) equates with meaningful consumer participation as defined in other areas of health service delivery. It is recognised that levels and models of consumer participation vary between service types and even between different residential rehabilitation services. In this regard there is a need for a better articulation of the models of consumer participation being adopted in various treatment contexts and the rationale underpinning these approaches.

6.3.3 Detoxification/Withdrawal Services

As with the other treatment settings, consumers from the detoxification service also showed an initial lack of knowledge of consumer participation. After the concept was explained, many still expressed less interest in participating in consumer participation and less enthusiasm for the general concept. Most were more willing to let staff make treatment or service decisions on their behalf, and also tended to state that if there were to be consumer representatives they should be 'ex-users' or 'stable'.

Similar to the other projects, the demonstration project at the detoxification service also experienced difficulty in meeting stated project goals and outcomes, and did not engage the local drug user organisation in their project. A significant issue in interviews with both consumers and staff was that of how to maintain consistency in consumer participation when consumers are only based at services for a relatively short period of time (on average one week) and are also very likely to be quite ill for a large proportion of this time. Given these circumstances alone, it would be very difficult to have meaningful engagement, training and an ongoing presence at services. For future reference it would be advantageous to examine ways in which these obstacles may be overcome. In particular, this is one service environment where the concept of accessing 'past consumers' of the service may have some application.

It should also be noted that detoxification services are also environments where fixed concepts such as 'current user', 'ex-user' could be problematic and act as barriers to consumer participation. The main reason for this is that consumers access detoxification services for many reasons, including for court

references, wishing to take a temporary break from licit or illicit drug use, wishing to detox from only one substance while continuing to use others, as an entry requirement for a residential program, while waiting for a place on a pharmacotherapy service, etc. This diversity also means that strict definitions of current or ex-user are unlikely to resonate with current or past consumers of detoxification services and could act as significant barriers to a group that is already difficult to engage in consumer participation.

6.4 The Concept of 'Stability'

6.4.1 'Stability' and Consumer Representation

The concept of 'stability' was raised by both consumers and staff at baseline and evaluation. Those who raised this as an issue appeared to place a good deal of importance on 'stability' and many seemed to regard it as being a critical factor for successful consumer participation in drug treatment settings. However, finding a working definition of 'stability' that took into account the diversity of opinion on this issue was very difficult. While there were some common themes and characteristics consistently referred to in the evaluation interviews as being the hallmarks of 'stability' for a consumer representative, there were also some fundamental philosophical differences in the views expressed on this issue.

For some staff and consumers, 'stability' specifically related to a state of being, such that the person — the consumer representative — is considered 'stable' in relation to their current drug-using patterns. For others, it was a much broader concept that included current drug use patterns but also seemed to include other lifestyle issues and attitudes, such as having a stable place to live, being employed, taking care of their children, and having a 'commitment' to what they are doing.

Among consumers, the concept also seemed to vary depending on the type or types of services they had experienced in the past or were currently utilising. Consumers from residential rehabilitation services held a common view that 'stability' meant total abstinence from drug use of any kind for a specified period of time. Whereas consumers from pharmacotherapy services were more likely to view 'stability' as including drug use patterns but not necessarily requiring total abstinence to be 'stable'. In many ways this dichotomy is not surprising, as for the most part it reflects the overarching therapeutic approach or philosophy of the respective services.

Staff also invested in the concept of 'stability' as a valued attribute for potential consumer representatives. As with the consumers, there was no real consensus among staff about this term and how it should be applied in the context consumer participation. There is some evidence in the evaluation that the concept of 'stability' was applied (albeit in an ad hoc manner) by some of the project sites when consumer representatives were selected. The high level of importance placed on this concept of stability was highlighted in one project where the selection of a consumer representative was significantly delayed due to concerns on behalf of the service that the person needed to be 'stable'. The service concerned claimed that despite an extensive recruitment process they were unable to attract or indentify a suitable current treatment consumer for the position. However, at evaluation at least one current consumer from that service stated they were and remained very interested in the position but were not informed or encouraged to apply when the position was advertised.

Given the potential for this issue to have a significant impact on consumer participation opportunities, there is a need for further discussion about the utility and relevance of this concept for consumer participation in drug treatment settings. In particular, there needs to be discussion about how 'stability' is defined and characterised; how stability is determined, and who should judge the 'stability' of an

individual consumer; and how 'stability' is managed over time in the context of a project or ongoing paid position. These questions will need to be identified and addressed in discussions with both staff and consumers before this concept can be usefully applied in this setting — or, indeed, abandoned.

The concept of 'stability' is already well-ultilised in clinical practice in the illicit drugs treatment sector as its corollorary, 'chaotic'. In this context, too, the concept has been the subject of much deliberation and debate. One of the main applications of this concept has been for clinicians to determine eligibility for take-away or unsupervised doses of opioid pharmacotherapies such as methadone and buprenorphine. Victoria is one of the jurisdictions that has developed a tool to assist clinicians in decision-making in relation to stability and eligibility for take-aways. Although this tool is considered useful in the context of clinical practice, its complexity and the individualised nature of the advice provided both serve to highlight the difficulties associated with attempting to use this concept in a systematic manner in consumer participation (Victorian Department of Human Services, 2006).

The concept of 'stability' and associated beliefs and assumptions about the levels of consumer interest in consumer participation was highlighted in the TSU Project: Phase One. Of interest was the fact that both staff and consumers held strong beliefs, largely based on generalisations about stability and capability, that most consumers would not be interested in consumer participation (AIVL 2008, pp. 86-87). These generalisations did not hold up when individual consumers were interviewed, but it did raise important questions about how assumptions, beliefs and generalisations among staff and consumers can act as a barrier to consumer engagement and involvement.

As a highly marginalised group in the community, beliefs about the capacities, skills and interests of illicit drug treatment consumers can often be driven by discriminatory attitudes and stereotypes. As highlighted in the policy audit for the TSU Project: Phase One, in areas of health service delivery to marginalised communities (such as drug users, people with mental health issues, etc), the relationship between attitudes and consumer participation is circular. In fact, in mental health, negative attitudes held by service providers have been shown to act as a barrier to genuine consumer participation (Mental Health Council of Australia, 2000).

Entrenched and internalised stereotypes about the capacities of other drug treatment consumers often drive consumer comments about the role of 'stability' in consumer participation. This is evidenced by comments from consumers in the TSU Project: Phase Two that suggest the 'stability' and, therefore, the 'suitability' of particular consumers to act as a consumer representative is associated with the type of treatment they are accessing. For example, as explored above, some consumers expressed the view that people who were in treatment for alcohol-related problems would make better consumer representatives than potentially less 'stable' opioid pharmacotherapy consumers.

Problems with the concept of 'stability' as a static measure for suitability and effectiveness are also highlighted by comments from consumers who are new to consumer participation. Consumers referred to how their capacity and interest in being involved in the demonstration projects changed over time with changes in their personal circumstances and growing awareness of the value of consumer participation. These comments show the need for flexibility and openness when considering and selecting consumers to act as representatives. Assessing people against a 'one-size-fits-all' concept of stability at a single point in time could not only result in a service overlooking an effective consumer representative but does not allow for change in people's lives.

As found in the TSU Project: Phase One, the most effective consumer participation is based not on assumptions, judgments or beliefs about person's capacity, interest or stability, but on open

communication and accessible pathways for engagement. Consumers of drug treatment services are a diverse population with different needs and a variety of skills and experiences to offer. Services need to ensure they have a range of engagement points and different types and levels of participation to suit the diverse needs of their consumers. This also means resourcing for consumer participation as core business rather than an added extra on the workload of an already over-stretched staff member. It means creating the physical spaces to allow engagement with consumers outside of one-on-one clinical interactions where concepts such as 'stability' take on very different meanings and can often act as a barrier to genuine communication. Finally, it also means providing opportunities for consumers to consult each other and build the skills necessary for effective consumer participation.

6.4.2 Being 'Fit' for Service

One of the more interesting developments that emerged across the two evaluation points was a shift in the focus of comments about the concept of 'stability'. In baseline interviews many staff focused on a perceived need for consumers to be 'stable' if they were to be effective consumer representatives. By evaluation however, this focus on the 'stability' of consumers had effectively dropped out of the data to be replaced with more of a focus on whether the service itself had the level of stability required to effectively involve consumers. This shift seemed to indicate a growing awareness among staff and services of the level of commitment and systems required across the entire organisation to effectively carry out consumer participation projects. In short, there seemed to be a shift away from whether the consumers were 'fit' to be consumer representatives to more of a focus on whether the services themselves are 'fit for service' — 'fit to conduct consumer participation projects'.

While this shift was not evident in all services, those projects that experienced difficulties certainly reflected this change of view. For example, comments by staff in evaluation indicate this growing level of awareness included comments on the lack of stability in staffing, lack of stability in organisational memory, projects passing through many hands, financial systems unable to cope with the requirement to pay consumer representatives in a timely fashion and a lack of appropriate record keeping for the projects.

Indeed, the difficulties encountered by one service in paying the promised reimbursement to consumer representatives placed this person in a highly vulnerable position if they chose to take issue with the service. Previous research has documented how clients of drug treatment services (particularly pharmacotherapy) perceive that their access to treatment is fragile and that staff can be punitive in their response to client distress or dissatisfaction (Treloar, Fraser, Valentine, 2007). It is conceivable that there may have been negative implications for the consumer representative if they had become upset or visibly distressed at the failing of the drug treatment service to meet its obligations.

This concept of services and systems being 'fit for duty' has also been examined in the area of HIV treatment adherence among injecting drug users in a development context. This work highlights that while much of the focus has been on the ability of the individual to adhere to treatment regimens, there has been little focus on the capacity of the treatment systems themselves to provide accessible and integrated treatment services that are responsive to patient needs. In his work on this issue, Wolfe states:

Labelling active drug users as socially untrustworthy or unproductive, health systems can create a series of paradoxes that ensure confirmation of these stereotypes (Wolfe, 2007).

One of the main implications of this reframing of 'stability' to be, in the first instance, about services being 'fit for duty' rather than commencing with a focus on whether consumers are 'fit to be consumer representatives', is that it offers services an opportunity to reflect and consider what they need to create an environment of engagement. This capacity assessment needs to occur before services consider undertaking consumer participation projects and should include:

• Training and capacity building for management and staff;

• Adequate resourcing for consumer participation activities;

• Commitment at all levels of the service to involving and valuing consumers; and

• Engagement with local drug user organisations.

Finally, the fact that this issue has been canvassed should not be read as a criticism of those services who applied to undertake the demonstration projects or as an attempt to characterise the projects as failures. In many ways, these services have displayed significant courage in taking on the challenge of consumer participation under the scrutiny of national evaluation. However, the above comments are aimed at encouraging critical reflection on a significant shift that occurred across a number of projects with the genuine hope that this experience can be used to improve consumer participation processes and outcomes in the future.

6.5 Power and Empowerment

Issues of power and empowerment ran throughout most issues and themes of consumer participation in the TSU Project: Phase Two. This issue was most evident in consumer interviews (at both baseline and evaluation) which showed a fundamental lack of understanding in regards to both the concept and practice of consumer participation. After an explanation of consumer participation was given by the interviewers, consumers expressed their support. However, in many cases, the consumers lacked confidence in their ability to participate in treatment decisions. While in some cases this lack of confidence related to the individual's life experiences and treatment journey, in other cases it was clear that a sense of confidence in relation to participation was linked to feelings of powerlessness.

Staff interviewed at both baseline and evaluation were significantly less likely to believe that there was an imbalance of power within their services, with many failing to recognise the potential power dynamics and the impact of this on consumer participation. Examples put forward for perceived equal power ranged from 'consumers being able to leave services whenever they chose', therefore being in 'voluntary stay' with regard to the residential rehabilitation service, to many pharmacotherapy service staff believing that the 'close relationships' formed with consumers enabled more of an equal relationship between the staff and consumers. When power differentials were acknowledged there was a divide as to whether or not these could be challenged. Some stated communication and honesty as the key to fostering equal relationships and overcoming these challenges, but others were less confident that power differences could be overcome — implying trust, power and empowerment were too entrenched in services to be changed overnight — or even at all.

As mentioned above, while many staff (and to a lesser extent consumers) did not acknowledge great differences in power standings between staff and consumers, there were many examples where this was evident. A fundamental reality of pharmacotherapy treatment that could not be ignored when considering the impact of power on consumer participation is the issue of physical dependence. Within pharmacotherapy settings, consumers are heavily reliant on the medications provided to them by

services. This factor alone does not lend itself to feelings of equality with staff by consumers, and there is the inherent threat that taking part in consumer participation could 'cost' someone access to their medication or other provisions that services provide such as take-away doses. Even within residential rehabilitation and detoxification facilities there are still similar constraints — speaking honestly about service deficits will not be looked upon favorably and could result in privileges (such as recreational time) being withdrawn and even removal from the service. While some services disagreed that this would happen, often consumers past experiences of stigma, discrimination and poor treatment meant that perceptions, not simply reality, could have a powerful effect on people's decisions to become involved in consumer participation, or not.

Many consumers seemed to be resigned to considering that changes to the way services ran would be out of their hands. Changes at the policy level were seen as too distant from the consumer experience or to input via a consumer participation process. In many interviews (at baseline and evaluation) the power imbalances were simply accepted by consumers as standard and even necessary, with many consumers believing and stating that staff knew what was better for them. In some instances staff were seen as 'peers' due to the knowledge of them being 'ex-users'. In addition to earlier discussions about 'who is a consumer' and when does someone become an 'ex-user', this issue raises another potential barrier to consumer participation. For example, if consumers consider staff (that they know to be 'ex-users') as their peers, then can these staff also reasonably represent them as consumers? Even if they are peers, first and foremost they are staff and this fact raises important questions about the potential crossing of professional boundaries and confusion of roles (i.e. can you be at once a consumer and a staff member, particularly in relation to consumer participation?). This question may be answered in the positive if you are working in a drug user organisation, but a drug treatment service is a very different context which it is argued fundamentally changes the power relationships and prevents such dual roles. This issue has also been explored in the section above on the role of staff who are ex-users and/or treatment consumers.

The staff interviews at evaluation also indicated that they witnessed the personal empowerment of those in the consumer representative role across the course of their projects. Paradoxically, the position of consumer representative can only be effective (powerful) if the individual is still recognised as a 'peer' by the client group. Being identified as 'one of them' (a staff member) effectively robs the position of credibility and, therefore, power among its constituents. A hypothetical variation on this theme was mooted by interviewees and might be termed the 'yes man': effectively an overly compliant peer chosen by staff to act as a token consumer representative. In both instances it seems that the 'voice' of the representative must remain identifiably 'ours' to consumers in order to remain authentic and empowered — as 'us' and not 'them'. Yet this in turn appears to draw upon and reinforce the very dichotomy (of staff versus client) that consumer participation purports to challenge.

The issue above brings into question the empowerment of consumers. As mentioned previously, many consumers were quite willing to let staff make decisions regarding services and treatment. This implies that services may not be doing enough to empower their consumers to make these decisions. Indeed, some staff in evaluation acknowledged power as a central issue in developing consumer participation and indicated that they found the consumer participation project challenging, as it required them to 'let go' of control. While power and empowerment issues in treatment services cannot be addressed easily, or quickly, it is suggested that it could be more effective if large-scale changes were made within organisation structures. Changes to current practices and policies ¬— such as core requirements to train (utilising drug user organisations) staff and consumers, and engage service consumers in meaningful levels of consumer participation ¬— would go a long way to actualising consumer participation as a

valid and highly worthwhile practice. Should this not be feasible then further research and project evaluations would be beneficial, at the very least to contribute to the limited research currently available on consumer participation and consumer representation in drug treatment settings.

6.6 AIVL Reflections on Demonstration Projects as Project Administrator

One of the significant distinctions between the TSU Project: Phase One and Phase Two is the fact that Phase Two focused on the implementation and evaluation of a series of demonstration projects whereas Phase One was a research project to map issues and attitudes in relation to consumer participation. The focus on implementing demonstration projects changed the nature of AIVL's role in the TSU Project: Phase Two from that of research investigator to project administrator. In contrast to the discussion points above, which specifically relate to the findings of the formal evaluation process, the comments below are a series of observations and reflections on project administration and working with the demonstration sites from AIVL's perspective. While these issues are not documented from an objective standpoint, they nevertheless contain important lessons for the future of consumer participation in drug treatment settings and therefore have been accorded an appropriate level of consideration in this report. In a number of places, the issues outlined below also have strong thematic connections with the findings from the baseline and evaluation interviews discussed above, and together this data forms an overall and realistic picture of the benefits and challenges of consumer participation in drug treatment settings. However, it should be noted that AIVL accepts the project sites may have a different and equally valid experience of the issues outlined below.

6.6.1 Involvement and Role of Drug User Organisations

One of the more disappointing outcomes from the demonstration projects was the overall lack of genuine involvement and collaboration between the project sites and the relevant local drug user organisation. This is not to state that there was no involvement or relationship between these key stakeholders, but it is worth noting that when reviewing the project as a whole, no project site really made the most of this valuable resource, and the engagement that did occur with drug user organisations was sporadic. The reasons for this lack of engagement seem to mirror many of the barriers and challenges to involvement experienced by individual treatment consumers including structural and communication barriers.

Concerns about how structural and communication problems can act as barriers to consumer participation both for individual consumers and drug user organisations was identified in the TSU Project: Phase One. The National Consultation with Consumer Organisations in the TSU Project: Phase One highlighted the need to develop 'pathways to support more positive and constructive communication' between consumer organisations and services. They stated that such pathways could act as a strategy to address entrenched attitudes, identify and remove structural barriers and increase meaningful participation (AIVL, 2008, pp.73-74).

Taking this into consideration, all project sites in the TSU Project: Phase Two were required in the EOI process to address how they would work with the relevant drug user organisation in their state or territory. All project sites were able, in a theoretical sense, to outline how they would encourage such involvement. Subsequently, the requirement to engage with the local drug user organisation was also written into the service agreements with each project. The question that arises then is why was the engagement with drug user organisations so limited across the projects? Of the five demonstration

projects only three sites (one in each of the three states engaged in the projects) had any contact with the local drug user organisation, and the engagement in one of those three sites amounted to only two meetings, initiated by AIVL, between the service and the local drug user organisation.

The reasons for the lack of user organisation involvement among the project sites that had little or no contact are likely to be explained with reference to existing roles and relationships between drug treatment service providers and service consumers. The TSU Project: Phase One highlighted the strong belief among many service providers that it was not 'the place' of consumers to have a role in decision-making with regard to service planning and delivery (AIVL, 2008, p.87). Similar sentiments were also expressed by service providers in the TSU Project: Phase Two. This attitude has also been highlighted in other studies relating to the culture of drug treatment services and how certain types of service culture can act to close off consumer roles and opportunities for service provider and consumer engagement (Treloar and Holt, 2006).

In this context, it is possible to envisage how such attitudes could be extended to relationships with drug user organisations and act as a very real barrier to engagement. If services do not support consumers taking a role in decision-making in relation to service planning and delivery, it follows that proactively seeking a relationship with the local drug user organisation may not be a priority for those service providers. It is possible this reluctance would be further underlined by the fact that the 'consumer relationship' in this case is even more likely than with individual consumers to result in consumer organisations asking for involvement in decision-making roles within the service. On the other hand, it is also possible that the problem of the consumer participation projects not being considered 'core business' by any of the services meant that there was not one staff member following up on contacts and liaison with the local drug user organisations and it therefore simply 'slipped through the cracks'. Either way, it highlights a problem with valuing the role and contribution consumers can bring to their services.

However, as outlined above, a number of project sites did include a reasonable degree of engagement with the local drug user organisation in their consumer participation projects. Of interest is the fact that both of these project sites had existing working relationships with the local drug user organisation. Indeed, one of the sites had already commenced discussions about another potential consumer participation project in partnership with the local drug user organisation prior to applying for the TSU demonstration project. From the evaluation data both the consumers and the staff in these services also seemed to have a greater level of awareness and understanding of consumer participation in the drug treatment context. This outcome is supported by available literature in the area of mental health and consumer participation which highlights the importance of 'practical experience' in changing attitudes towards the value or benefits of consumer participation, particularly in relation to consumers having a role in decision-making (Northern Area Mental Health Service, 2003).

While these sites were able to utilise existing relationships with their local drug user organisations as a platform for further engagement, it is noteworthy that even in these projects the involvement of the drug user organisations was not consistently sustained across the projects. The reasons behind this include the chronic turnover of staff in one service, which made ongoing involvement and stability of the relationship impossible, and a lack of resourcing in the drug user organisations which severely reduced their interest in and capacity to participate in a meaningful way in the project. While the negative impact of staff turnover is addressed elsewhere in this section, the lack of adequate resources to support the involvement of drug user organisations in the demonstration projects was a significant problem.

In addition to agreeing to involve drug user organisations in their demonstration projects, services also agreed to ensure that some of the available project funding would be used to resource drug user organisations for the roles they were asked to undertake within the projects. As outlined above, the majority of services did not engage the local drug user organisation in a meaningful way and therefore resourcing this role did not arise. However, a lack of resourcing did affect at least one of the projects and this example highlighted the importance of ensuring adequate resourcing for drug user organisations if they are expected to support the development of consumer participation in treatment services.

This is consistent with the findings in the TSU Project: Phase One which identified the lack of resourcing for consumer participation work as one of the 'main reasons why they struggle to effectively coordinate consumer participation efforts across the drug treatment sector' (AIVL, 2008, pp.89-90). Although the service involved did offer some resourcing for delivery of training for consumer representatives, the overall level of project funding meant that the service was not able to offer the level of resourcing needed to cover the 'real' cost to the drug user organisation of designing and delivering the training. At the heart of this problem is the fact that the vast majority of drug user organisations do not receive 'core capacity' funding for consumer participation work and this makes it very difficult for these organisations to prioritise participation in projects conducted by individual treatment services. In this regard, what can appear to be a lack of interest in participating from drug user organisations can in fact be a lack of ability to participate due to resourcing limitations.

In the end, regardless of the reasons, all five demonstration projects suffered from a lack of sustainable involvement from the local drug user organisation. The significant role that consumer organisations have played in increasing access to and uptake of health services and improving health outcomes for Australians is well documented (Consumer Focus Collaboration, 2001). A consistent theme across the TSU Projects: Phases One and Two is an ongoing reluctance to involve drug user organisations in consumer participation activities within the drug treatment sector.

This is further compounded by side discussions about which consumers drug user organisations can or do represent, and how to address the needs of those consumers who are not thought to be represented by such organisations. However, it is up to drug user organisations to decide who they purport to represent. Whether this is accepted by others or not is a separate matter, but it does not change the way that drug user organisations view themselves or those they seek to represent. Too often it seems that discussions about the diversity of treatment consumers are used to avoid taking action on the central issue — that with proper resourcing, existing drug user organisations would have the capacity (and view themselves) as the appropriate entities to represent treatment consumers with illicit drug dependencies. The apparent absence of a group to represent alcohol treatment consumers does not diminish this fact. It is time to move away from continual and unproductive discussions about the 'absences' and 'gaps' in drug user organisations to an acknowledgement of their role and value. In short, it is time to acknowledge and make use of what is there rather than focusing on what isn't.

While there were some exceptions, the majority of treatment services involved in the TSU Project: Phase Two chose to conduct their consumer participation projects without the meaningful involvement of local drug user organisations. This was the case despite:

• All projects experiencing problems with accessing and engaging their service consumers;
• At least two services experiencing problems recruiting suitable consumers to take up paid consumer representative positions; and
• A number of services complaining about a lack of resources and skills among existing staff to support consumer representation and the project generally.

The above issues are significant as they are all issues that could be successfully addressed by establishing and adequately resourcing an effective working relationship with the local drug user organisation.

This outcome reflects an increasingly urgent need to build greater awareness, understanding and, most importantly, acceptance among services and funding bodies of the role that drug user organisations can and must play in building consumer participation in drug treatment settings. Ultimately however, this will require a change in the culture of treatment services to allow consumers and, by extension, their representative organisations to take an active role. Other areas of health service delivery have managed to bridge this gap with very positive results for both service providers and service consumers (NAMHS, 2003). In this regard, it is positive that at least three services mentioned in evaluation that the experience of other sectors in consumer participation, particularly mental health, could provide useful lessons for the drug treatment area. That said, addressing the issues and concerns outlined above will require transformation at the level of both policy and practice.

Finally, it should be noted that transforming the relationship between drug treatment services and drug user organisations will require good faith, trust and commitment from all parties. The TSU Project: Phase Two evaluation data reveals that meaningful collaborations between treatment services and drug user organisations not only results in a greater awareness of the potential benefits of consumer participation for all involved, including consumers, but also has a positive effect on how consumers view the work and role of drug user organisations. Some consumers expressed the view that involvement in the consumer participation project at their service not only raised their awareness of their local drug user organisation, but also provided a 'way into' the drug user organisation as they could now see the tangible benefits of being involved.

While the demonstration projects funded for the TSU Project: Phase Two did not necessarily achieve the level of project outcomes specified in the original project plans and logframes, overall the project has begun the process of identifying both the barriers and incentives to consumer participation projects in this setting. With both treatment services and drug user organisations having a good deal to gain from collaboration in this area, the future of consumer participation in drug treatment services will rely on the development of effective working relationships between these two key stakeholders. Despite some existing relationships, by and large this work still needs to be undertaken.

6.6.2 EOI Process, Project Plans and Implementation

The TSU Project: Phase Two was unique in that it focused on the implementation and subsequent evaluation of five consumer participation demonstration projects in a range of drug treatment settings. The process for selecting the demonstration sites involved an advertising and EOI process followed by an assessment and selection process. This backdrop to the projects is important largely because it goes to the heart of some of the issues experienced by AIVL as the project administrators.

The evaluation data reflects an inconsistency across all projects in relation to the agreed project plans and logframes compared to the actual outcomes and achievements of the projects. While AIVL received a good level of interest from drug treatment services when the advertising and EOI process was conducted (and found services to be co-operative and enthusiastic when negotiating and finalising the project plans), it subsequently experienced a range of complications with the projects from a project administration viewpoint.

High staff turnover in key project positions caused long delays to one project and, from a project administration perspective, this appeared to be further complicated by the lack of an adequate handover

to new staff. This not only caused further project delays but also resulted in confusion and misinformation among consumer participants in relation to project activities and arrangements. The impact of this situation can be seen in the evaluation data which reflects a 'change of heart' from consumers between baseline and evaluation data collection as their initial enthusiasm and commitment to the project wanes due to a drop in project momentum and confusion and delays in agreed consumer payments.

While the service acted to address the staff vacancies as quickly as possible, these types of problems are part of the reality of conducting consumer participation projects within large treatment services. Consumer participation activities are unlikely to be well-resourced or even resourced at all within most treatment services. Inevitably, staff will move on to new opportunities creating vacancies not only in their primary position but in the 'associated' roles they carry, such as consumer participation projects. In the end, the root of the problem may be associated, once again, with the overall lack of adequate resourcing and philosophical support for consumer participation activities within treatment services rather than what appears to be the problem on the 'surface' — that is staff vacancies.

The funding for the demonstration projects as a whole was insufficient and meant that projects were only provided with a 'contribution' towards project costs from AIVL. As the project administrators, AIVL was restricted in the funding that could be provided to services by the amount of overall funding received for the TSU Project: Phase Two. AIVL was clear at the EOI stage that the funding available for demonstration projects was a 'contribution towards project costs'. However, in offering this contribution there was an expectation that services would already have or would be in the process of establishing their own investment in consumer participation as an essential rather than 'optional' aspect of a quality treatment framework. Indeed, all of the services selected for the TSU Project: Phase Two identified in their EOI that they had already made some level of commitment to consumer participation within their service model.

A significant part of the rationale for this approach was that the TSU Project: Phase One found that engagement in lower level consumer participation activities (according to the definition and model adopted for the project) was relatively commonplace among drug treatment services (AIVL, 2008, p.84). Therefore, it was agreed that the TSU Project: Phase Two would focus on services that were ready to move beyond lower level participation activities. On this basis, the TSU Project: Phase Two assumed a level of existing investment in consumer participation and presented services with an opportunity to 'start-up' higher level activities or 'value-add' to their existing consumer participation activities. It would not, however, provide the basis for large-scale projects that were commencing from 'day one'. The concept of providing extra funding to support services to 'start-up' consumer participation activities was also strongly identified in the TSU Project: Phase One Report (AIVL, 2008, p.89).

It is interesting to note that comments from services in the evaluation data continued to identify the need for 'start-up' resources to build support and commitment for consumer participation before being able to embed it as a standard practice within the organisation. Given that all of the services were provided with funding as part of their participation in the TSU Project: Phase Two to value-add to existing and 'start-up' higher level activities, it must be asked whether resourcing problems are the only barrier to embedding consumer participation in drug treatment settings. Perhaps it is possible that although a lack of resourcing is a significant part of the problem, it is not the total picture. For example, are there problems at the policy or structural level that are preventing meaningful consumer participation being put into practice in the drug treatment context despite a level of resourcing being made available?

In evaluation some services identified the importance of flexibility in project administration as a very important factor in allowing under-resourced treatment services to adapt projects as needed and in response to client needs. While AIVL agrees with this principle and did attempt to provide a flexible environment for project implementation, concerns emerged across most projects in relation to the seeming lack of involvement of consumers in project planning and a lack of response to progress reporting requirements. Despite requests for update reports to allow AIVL as project administrator to provide targeted support and trouble-shooting for projects, only one of the five projects provided any of these reports.

AIVL had attempted to keep the progress reporting for the projects to a minimum — requiring only a brief update on progress after the first month and one at another point across the six-month projects. In addition, as AIVL was aware of the negative impact onerous reporting requirements could have on the small-scale projects, the request to provide progress reports was not included in the logframes as a formal project outcome but rather as a more informal agreement with each of the project sites. The AIVL Project Officer contacted the sites as appropriate, based on their commencement date and relative progress, to seek brief, written progress reports. While sites were willing to provide a verbal update of progress, only one site complied with the request for the written updates.

Given the numerous comments in evaluation relating to services being under-resourced and under-staffed, it is possible that projects found it difficult to justify and/or prioritise progress reporting for a relatively small amount of funding. The negative impact that unnecessary reporting can have on project outcomes and the need to ensure reporting does not place a disproportionate burden on small projects and organisations has been well documented in numerous studies within the health sector (New South Wales Council of Social Services, 2009). In this regard, it is a legitimate concern for services implementing small-scale consumer participation projects. Nonetheless, if this was a problem it needed to be raised with AIVL and addressed through a renegotiation of appropriate milestones rather than by neglecting or refusing to report.

The lack of regular progress reporting meant that in a project where there were five different sites across three states, AIVL was effectively locked out of the support role it could have provided to services in the implementation of their projects. AIVL's budget, too, was extremely limited and without funds to regularly visit the projects, and in the absence of written progress reports, a 'disconnect' developed between the projects and AIVL as the administrators. While AIVL accepts responsibility for its part in creating this breakdown in ongoing communications, it also needs to be acknowledged that the project sites did not make active attempts to contact AIVL and address this situation.

Verbal reports were useful when provided but this relied on the ability of the AIVL Project Officer to reach relevant contact people at each of the sites within a reasonable timeframe. As the AIVL Project Officer was a part-time position and services are busy and under-resourced, this was often difficult. Verbal reports also increased the chance of important issues being lost in translation or overlooked as they were communicated from the project site to the AIVL Project Officer, and then onto other AIVL staff and staff from the NCHSR. When this issue is coupled with the general lack of engagement with local drug user organisations identified above, the result was an unfortunate dismissal of a good deal of expertise and support in relation to consumer participation that could have been provided by AIVL and its members.

In addition to the concerns about reporting, the evaluation data raises questions in the majority of cases about the level of consumer involvement in the development of the project plans at any stage

of the process. Statements by services admitting a lack of genuine involvement of consumers when planning their projects and referring to consumers as typically being engaged at the 'rubber stamping stage', raise concerns about the quality of some of the projects conducted. It is accepted that consumer participation in drug treatment settings can mean it takes time for understanding, relationships and trust to be established. In this context it can be difficult to find consumers who are interested and willing to act as consumer representatives. However, what is less clear is why the opportunity to revise project plans with genuine consumer input was not taken up after the project commenced and once a number of key consumers were involved?

Evaluation data from both consumers and staff reflected an absence of consumer involvement in key project activities, particularly those in the mid- to high-level range involving decision-making roles such as having input into the job descriptions for consumer representative positions. This resulted in many consumers having very limited knowledge of the project, and many framing the project outcomes more in terms of individualised self-help and support rather than as active involvement in service planning and decision-making. In some services, this view was reinforced by the belief of some staff that there are certain roles that are 'staff only' and 'inappropriate' for consumer involvement. The view that there are certain roles that are 'inappropriate' for consumer involvement was also a theme expressed by some services in the findings from the TSU Project: Phase One (AIVL, 2008, pp 57-60).

While it is acknowledged that in all health-care settings there are roles and responsibilities that are appropriately restricted to trained professionals, the roles being referred to in relation to these projects do not fall into this category. They are roles and responsibilities that many other areas of heath service delivery have designated as not only appropriate to be undertaken by consumer representatives but frequently result in better outcomes for both consumers and services when undertaken by or with consumers (Norman, J et al., 2008). These roles include input into project plans, consumer representative position descriptions, service planning committees, staff training sessions, service policies and staff recruitment, etc.

In addition to the lack of consumer involvement, in many cases the projects had also been developed without the input of the majority of staff. Evidence of this lack of staff involvement was highlighted in the evaluation process and is discussed further in Section 6.6.3 below. In some cases, services did not have effective strategies for encouraging and supporting communication among staff. This suggests that many of the services were not well-placed to embark on medium-level consumer participation despite indications to the contrary in the initial project proposals. Developing clear and effective ways to communicate with staff and consumers within services is likely to be central to successful consumer participation and, therefore, 'pre-consumer participation activities' aimed at developing engagement and communication strategies among consumers and staff should be first priorities.

It should also be noted that all services involved in the TSU Project: Phase Two had at least one key staff member who was committed to and interested in consumer participation within the service. By and large it was these staff members who drove the EOI process and took responsibility for developing the project plans, negotiating the logframes and liaising with AIVL and other staff within their service. Despite the best intentions of a few enthusiastic staff in the services involved, much of the activity being labelled as 'consumer participation' over the course of the evaluation was shown to be largely staff-driven project activity designed primarily to meet accreditation standards, internal evaluation needs and externally imposed performance measures. Some projects had more genuine consumer involvement than others but no project had a strong sense of consumer ownership or being truly 'consumer-driven'.

The lack of consumer ownership over the activities and outcomes of the majority of the TSU Project: Phase Two demonstration projects is highlighted by the lack of awareness and understanding among consumers identified in Section 6.2 above. A few understood the purpose of the evaluation process but most did not and thought that the evaluation was an evaluation of the service, not of the consumer participation projects. Outside of a very small number of consumers who were employed in paid consumer representative roles, the majority of consumers interviewed had little or no knowledge of the consumer participation projects overall, let alone any involvement in developing the project activities and outcomes.

This situation highlights the level of training and capacity building that is needed among staff and consumers but, importantly, also among senior management and funding bodies in relation to consumer participation. Such training could support an understanding of consumer participation as a fundamental activity in its own right — with its own benefits and value — not just as a way to meet service accreditation and/or funding outcomes and deliverables. The need to reposition or shift the mind-set about consumer participation as being an 'optional extra' or done as a 'favour' to consumers was another underlining theme identified by AIVL and backed up by the evaluation data. In some of the services there appeared to be a lack of fundamental support and engagement in the project from senior management resulting in a general deprioritising of the project. This was reflected in comments from staff about a lack of support for consumer participation as 'core business' within the service, staff writing project plans in isolation, and little or no evidence of action taken by management in relation to 'white-anting' or outright refusals to participate in the projects by other staff.

Consumers interviewed in evaluation also identified this important issue. Consumer representatives involved in one project with high levels of staff turnover recalled the project as feeling 'rudderless' at times due to the overall lack of organisational investment in the project. These comments indicate a belief that the negative impact of staff turnover during a consumer participation project could be minimised, providing there is a strong commitment from senior management to ensure consumers feel supported and valued while new staff are recruited. Consumers also highlighted the potential for even enthusiastic consumers to gradually lose interest if there appeared to be little progress within the project. This is a major concern given that both consumers and staff identified the difficulties associated with getting consumers interested and involved in ongoing consumer participation roles as opposed to participating in one-off surveys or informal discussions.

These experiences are contrasted with the comments from consumers involved in one of the projects with a good level of senior management and organisational support. In this project, consumers identified the importance of staff support and feeling trust and commitment at a service or organisational level. As identified in 6.6.1 above, drug user organisations could play an important role in building an understanding of the potential benefits and value to the service of consumer participation. Interestingly, the above project where consumers identified a high level of staff and management support was one of the demonstration projects that involved the local drug user organisation in the development of the consumer training for the project.

From the vantage point as Project Administrators, AIVL strongly identified the need for organisational change and capacity building in relation to consumer participation for most services. Very few staff at baseline identified the need for management or staff training in this area, however there was some shift in this view at evaluation. This shift supports the view articulated in the TSU Project: Phase One

and consumer participation projects in other areas of health service delivery that an understanding and valuing of consumer participation often only comes after services have had some practical experience of engaging with consumers (AIVL, 2008, p.25 and NRCCPH, 2004).

In some cases, the existence of consumer charters of rights and responsibilities and/or quality frameworks requiring consumer participation were seen as sufficient evidence of organisational commitment to consumer involvement. Others, however, recognised the need for cultural change within their services before such policy frameworks would result in the meaningful involvement of consumers. The TSU Project: Phase One also showed that the mere existence of policies identifying the need for consumer participation did not necessarily result in a valuing of consumer participation by the service in a practical sense (AIVL, 2008. pp.85-86).

6.6.3 Evaluation Process

As the Project Administrators, one of AIVL's roles was to organise the logistics for the evaluation process. This involved contacting the demonstration sites to arrange two rounds of data collection — at baseline and then at evaluation towards the completion of the project timeframe. The data collection methodology is outlined in full in Chapter 4 of this report. A number of issues were highlighted during the process of coordinating the data collection which, although largely administrative in nature, have implications for the larger themes explored in other parts of this section.

Despite the fact that each of the project sites had designated and agreed project contact staff, at the time of organising the baseline and evaluation data collections AIVL experienced difficulties in making contact with these staff in a number of the sites. As identified above, the TSU Project: Phase Two had limited resources and for this reason AIVL aimed to provide a degree of flexibility for the project sites in relation to the timing of their data collection. However, there were important ethical obligations guiding both AIVL and the NCHSR to ensure that all data collection was conducted in accordance with strict ethical guidelines for evaluations of this type.

While two project sites met all evaluation requirements and responded in a timely fashion to all AIVL requests to schedule data collection points, unfortunately AIVL experienced moderate to significant delays in the three other project sites. It should be noted that one project site in Victoria experienced unforeseen delays to their project associated with the Victorian bushfires, which also affected scheduling for the second data collection point. However, this project site still worked effectively with AIVL to schedule all data collection points in a timely manner. Despite this, delays in contacting and therefore scheduling the evaluation points at the three other services ultimately caused irreparable damage to the overall timeframe for the TSU Project: Phase Two and resulted in AIVL having to seek a variation to contract to extend the project and deliverables. Some of the delays and problems included the inability to make contact with project staff via email or telephone for more than four weeks; scheduling data collection points to have them cancelled on the day AIVL and NCHSR staff were due to travel; and ongoing delays to scheduling of data collection points due to constant turnover of project staff.

In addition to the above problems, a number of concerns also surfaced once AIVL and NCHSR staff arrived at the project sites for the scheduled data collection. At all but one project site, staff at reception or other first points of contact did not seem to be aware of the project or know who the relevant contact person was for the project. Further, the majority of staff at two project sites also seemed to have little or no awareness of the scheduled evaluation. These occurrences raise a number of questions about

the consistency and quality of the projects in these sites, including why were so few staff aware of the projects, and what were the implications for the ongoing progress of the project if the single responsible staff member needed to take leave or resign from their position?

These questions were somewhat answered by the fact that the project experienced a high level of staff turnover, with at least three different project staff. In evaluation, consumers involved in this project expressed highly divergent views about their involvement in — and the quality of the project between — baseline and evaluation data collection. At baseline consumers were enthusiastic, committed and expressed a sense of empowerment about the possibilities of the project. In evaluation, the consumers were difficult to locate for interview and those who did come forward expressed disappointment with how the project had been managed, the lack of continuity and the fact that commitments made to consumers about payment and work had not been honoured.

At baseline and evaluation, five consumers were interviewed from each of the demonstration project sites. The project sites were asked to provide five consumers, preferably all directly involved in the project, for interview by the evaluators. Of concern was the fact that all project sites seemed to have difficulty in finding five consumers for the evaluation interviews who had been directly involved in the consumer participation projects. Although most of the project sites were able to provide one consumer, often a paid consumer representative, to interview specifically about the demonstration project, no site was able to provide five or even a majority of consumers who had been involved in the project. Of the consumers who were interviewed, a majority at all project sites seemed to have little or no knowledge of the project.

While these issues have also been explored above, they require some further comment as they do have implications for the quality of evaluation. The evaluations took longer than expected due to having to return to one site for follow-up interviews and having to take extra time to explain the focus of the evaluation to consumers. This would no doubt have been different if consumers who were directly involved in the projects could have been interviewed. Although the reasons for not being able to provide relevant consumers for the evaluation interviews varied from site to site, the major reasons included that the project had not yet properly commenced or interviews with appropriate consumers could not be arranged as services had found it very difficult to access and involve consumers in the projects. While not seeking to make 'excuses', one of the project sites also highlighted the difficulties associated with recruiting consumers to be involved in ongoing consumer participation projects as opposed to one-off surveys and focus groups.

From AIVL's perspective as Project Administrator these concerns also linked to the issue outlined above in relation to consumer involvement and ownership of the demonstration projects. While AIVL fully acknowledges the barriers to conducting consumer participation projects in drug treatment settings, the difficulties in accessing informed consumers for the evaluation interviews at the very least raise questions about the priority given to these projects by the services involved and the quality of the engagement that occurred.

Finally, it should be noted that both AIVL and the NCHSR also experienced staff turnovers during the TSU Project: Phase Two. While staff changes during time- and resource-limited projects always create logistical and strategic challenges, in both cases replacement staff were located, briefed and in place with little or no impact on the overall timeframe and with no significant break in contact with demonstration project sites. The major negative impact of the AIVL staff changes on the overall project

was that email updates to the PAC and monitoring calls to the project sites were less frequent than planned. While this was not ideal, it did not affect the implementation of the demonstration projects and both face-to-face PAC meetings were held at the planned project points — at project commencement and at draft final report stage.

6.6.4 Expectations of the Project

Following on from the issues raised above about the degree of ownership over the projects by services and consumers, this final section explores a range of issues in relation to project expectations. One of the key issues for AIVL as the Project Administrators was the degree to which the demonstration sites took responsibility for their projects and their outcomes at evaluation. As noted above, demonstration sites were selected based on an EOI and independent selection process. The interest in conducting the consumer participation projects was more than twice the amount that could be funded within the project budget. The result was that AIVL had to unfortunately reject numerous EOIs from enthusiastic and highly regarded drug treatment services as only five projects could be selected.

This background context is very relevant as a number of concerns have emerged across the project, in many but not all project sites, about the need to improve:

•	The level of senior management commitment to consumer participation;

•	The overall culture and environment in drug treatment services to better support consumer participation; and

•	The degree of involvement and therefore ownership of consumers in consumer participation projects in drug treatment settings.

Despite applying to conduct the project and putting considerable effort into developing project plans and negotiating the project logframes, AIVL did not experienced the same level of commitment from a majority of the projects in the project implementation phase. At certain points in the project implementation, AIVL was forced to reiterate to two of the sites that the demonstration projects were not 'AIVL' projects but their projects. It seemed at these two sites, at least, there was an expectation that after being selected to conduct their project, AIVL would work with them directly on the implementation phase. Not only was this inappropriate as AIVL is a national organisation, but also because AIVL would be playing a strong role in the evaluation of the projects through the consumer interviews. It was this separation of roles that was behind the rationale to require all project sites to work in collaboration with their local drug user organisations. Such arrangements would have established sustainable, locally relevant relationships between consumers, consumer organisations and drug treatment services.

AIVL also had to manage and modify its expectations of the project outcomes during the course of the demonstration projects. As already outlined above, all of the sites selected were required to demonstrate their existing commitments to low-level consumer participation activities and their interest in utilising the TSU Project: Phase Two to build on and expand these activities. The services not only offered different types of treatment services but they also had different levels of experience and development in relation to consumer participation and involvement. From the project plans submitted and the baseline interviews it was clear that some services had a higher level of senior management support for their project, existing relationships with local drug user organisations, and more established communication channels with their consumers.

In this context it was surprising that none of the projects seemed able in evaluation to fully demonstrate that they had achieved all or even most of their original project outcomes. Why was it that even those services that seemed to have some of the key indicators for successful consumer participation in place at project commencement were still unable to translate this advantage into clear and tangible project outcomes? Certainly, staff in some services claimed to have achieved significant results from their projects with staff from one service remarking on the fact that one client was so committed to the consumer participation project that they extended their stay in the service to continue their involvement. Regardless of this situation, this was not one of their project outcomes and for this service, and all the other project sites, consumers across the board did not verify the degree of activity and outcomes that key staff outlined in evaluation interviews.

AIVL acknowledges that there may be differences in the way that staff and consumers both perceive and articulate project outcomes. It is also acknowledged that not all consumers interviewed at the evaluation stage contradicted the statements and views of service staff. However, the difficulty is that the differences greatly out-number the similarities and they are significant and point to fundamental problems with communication between consumers and services. These communication barriers seem to be heavily associated with the existing roles and relationships between service providers and consumers. It seems that even where there is willingness to explore these roles, the TSU Project: Phase Two demonstration projects were not able to break through these barriers despite the best of intentions. This is supported by many comments made by both parties in evaluation, with staff acknowledging entrenched attitudes and power differences, and consumers expressing hope for a breakdown of these barriers and differences. Once again, these same issues and hopes were also articulated in the findings of the TSU Project: Phase One (AIVL, 2008, pp. 87-89)

Where does this leave the ideal of consumer participation in drug treatment settings? Is it impossible to genuinely involve consumers of drug treatment services — regardless of the service type — in the decisions about their service and their treatment? Are the treatment service models incapable of coping with the openness required for such engagement to work? Although it could be argued that some, even many, of the conclusions drawn about the demonstration projects in the TSU Project: Phase Two could indicate that consumer participation in illicit drug treatment services is not possible, this conclusion seems wholly unsatisfactory.

While all the services were committed to their demonstration projects, in practice many struggled to implement their projects and have not achieved the outcomes that they or AIVL had hoped would be achieved. However, it is important to acknowledge that these services have, for the first time, opened themselves to what it might take to make consumer participation in this context a reality. It is promising that the project sites identified in evaluation that they had underestimated the demands on the organisation, particularly at the 'higher levels' and that they needed to do further work on developing strategies for engaging consumers outside of the therapeutic or clinical environment. It is also important that a number of the services stated they were surprised and encouraged by the positive feedback and enthusiasm of consumers and that this gave them encouragement to keep moving forward.

This was the first national project to conduct a series of demonstration projects to support consumer participation in drug treatment settings. Many problems and barriers have been uncovered. We cannot pretend these barriers and problems are not present simply because we wish it so or because it might upset some services, staff or consumers. However, it is possible to take these challenges and commit to

the process of dismantling and addressing them one by one if necessary. Some of them are significant challenges for the drug treatment sector. Changing the culture of drug treatment services to open up communication and trust between staff and consumers will not be easy, but any steps in that direction will open the possibility of consumers having a stronger voice in the future. Some services are already making steps in this direction, but the need to continue the steps towards consumer participation in drug treatment services is probably articulated best by a consumer from one of the demonstration projects, who said:

> *'I think what I'm hoping it will achieve is a common ground for staff and consumers to work out things, like you know, how do you put it into words? It's like an even plane so everyone's on the same, like no-one's better than anyone, no-one's — even though this person works here and you're a consumer, you both got the same rights and you're both equal. You don't have to sit there, you know put your head down and think "oh they're the staff, I can't say anything what if they take my kids? What if they do this? What if they do that?" You know...'*