

Consumer

Participation

Supporting Evidence

This document provides further Supporting Evidence for the UnitingCare ReGen (ReGen) Consumer Participation Position Statement around the expansion of consumer participation in Australia.

Introduction

Consumer participation in health is an essential principle of health development, clinical governance, community capacity building and the development of social capital, as well as being an important democratic right (Victorian Government, 2009^a).

Who are consumers?

There are a number of different words used to describe people that engage with the AOD sector, and this can sometimes be confusing. The Association of Participating Service Users' *Straight from the Source: A practical guide to consumer participation in the Victorian alcohol and other drug sector* (Clarke & Brindle, 2010) defines the terms as follows:

Consumer

A consumer is someone who uses, has used, or is eligible to use alcohol and other drug services. This term also includes the family, friends and significant others of those who are eligible to use AOD services, as well as other people affected by AOD policy and laws, whether or not they directly access these services themselves.

Service User

A service user is a person who uses or has used AOD services.

Client

A client is a person who has used a particular AOD service.

Much of the research in this area uses the all-encompassing term 'consumer participation', and so for clarity consumer will be the preferred term in this document. This is also sometimes referred to as 'community participation' or 'citizen participation'.

What is consumer participation?

In the Declaration of Alma-Ata, WHO declared that 'people have the right and duty to participate individually and collectively in the planning and implementation of their health care' (World Health Organisation, 1978). While there are a variety of understandings of what consumer participation means, the following provides a good generic definition:

The process of involving health consumers in decision making about health service planning, policy development, priority setting and quality in the delivery of health services
(Commonwealth Department of Health and Aged Care, 1998)

Despite the early formation of AOD-focused self-help groups such as Alcoholics Anonymous, the AOD sector is possibly one of the last of the healthcare sectors to include formal consumer participation (Clarke & Brindle, 2010). In the late 1980s, peer drug user groups such as the Australian Intravenous League (AIVL) and Harm Reduction Victoria (then known as VIVAIDS) were formed. These groups developed innovative approaches to peer education and community development around harm reduction practices (AIVL, 2010, Harm Reduction Victoria, 2010).

Clarke & Brindle (2010) define 'consumer participation' in the AOD sector as the process of including consumers in decision making around:

- Their own treatment
- Service planning, development, delivery and evaluation
- AOD policy
- AOD research
- Education and training of AOD professionals.

Benefits of consumer participation

Consumer participation is based on principles of respect for a person's right to self-determination (Clarke & Brindle, 2010). Consumer participation is not only a basic human right; it is also consistent with the empowerment model and strengths-based approaches widely considered to be the most appropriate for working with stigmatised clientele, such as individuals with problematic AOD use (Mullaly, 1997, McCashen, 2005). It enables change, rather than dispenses a cure.

This participation is reflected in person-centred planning and goal setting approaches, unlike models where an 'expert' determines what treatment is offered to service users in a 'one size fits all' approach. Person-centred strategies prioritise the expression of personal needs, goals and aspirations. They are not new concepts but are increasingly based on evidence that this level of engagement and tailoring improves treatment retention and outcome (Miller et al. 2005).

Increasing consumer participation in an organisation increases the transparency and makes the service more accountable, which results in better services and improves quality and safety (Victorian Auditor-General, 2012). Participatory roles can and should also have an enhancing effect on the individual (Rance & Treloar, 2015), and can provide structured pathways for consumers to develop workplace skills and gain useful experiences which may lead towards employment. Consumer participation supports recovery and reintegration.

Whilst there is still a scarcity of published research into this area, particularly in terms of AOD treatment services (Rance & Treloar, 2015, Ti et al, 2012), there is a growing evidence base documenting the benefits of consumer participation. Research by Brener et al (2009) provides evidence to support the importance of consumer participation for clients in treatment, whilst AIVL (2011) found that consumer participation led to gains in self-confidence and empowerment.

According to research, consumer involvement in organisations has led to:

- Improved retention in treatment
- Higher levels of client satisfaction

- Reduced client contact with the criminal justice system
- Increased progression to education, training and employment (Hinton, 2010)

Models of participation

It is widely acknowledged that there is no 'one size fits all' model of consumer participation (Hinton, 2010, Department of Health, 2009). AVIL (2008) suggest the following model for consumer participation, which follows Arnstein's ladder of citizen participation. The model shows different levels of consumer, as well as examples of activities associated with each degree of participation:

Degree of Consumer Involvement	Type of participation	Example of Activity
HIGH	<i>Activities in which consumers share in decision-making</i>	<p>Consumer representatives involved in service planning committees</p> <p>Consumer representatives attend staff meetings:</p> <p>Consumer representative involved in staff recruitment either contributing to interview questions or a member of interview panel</p> <p>Consumer representative involved in staff performance appraisal</p>
MID	<i>Activities in which consumers have non-decision-making roles</i>	<p>Consumer involvement in resource development: Consumers involved in writing or reviewing written materials such as brochures, fact sheets, newsletters, magazines or educational resources.</p> <p>Consumers involved in staff training: Consumers involved in determining the content of training that is directly relevant to consumers and/or their views on treatment for service providers.</p>
	<i>Activities that promote and support consumer involvement</i>	<p>Consumers are supported to conduct their own group activities: A service has ways to help consumers facilitate and run their own support groups (e.g. fitness groups, mums' and dads' groups) such as providing space, training or transport.</p> <p>Service displays user group publications – consumer forum: The service displays or makes available in other ways the publications of drug user organisations (e.g. Harm Reduction Victoria, NUAA).</p>
LOW	<i>Activities concerned with providing information to or</i>	Consumer councils: Committees or groups of consumers whose role it is to advise the service about how services and programs are run.

	receiving information from consumers	<p>Forums: Open meeting in which consumers can express their views about how services or programs are run.</p> <p>Surveys: Surveys that specifically ask consumers for their opinions about how programs and services could be improved.</p> <p>Suggestion box: The service provides a box where consumers can leave written comments regarding their views about how the service or programs are run and suggestions for changes and improvements.</p> <p>Complaints process: The service has put in place a process for consumers to register their complaints about the delivery of the service.</p> <p>Produce resources for consumers that include information about service planning: The service has written or produced its own brochures, fact sheets, newsletters or magazines that specifically include information about changes to the policies and programs of the service.</p>
	Consumer participation is built in to the values and policies of the service	<p>Consumer participation incorporated into the vision or mission statement/consumer charter of rights: A document is produced outlining client/patient rights, responsibilities and expected levels of service.</p>

It should be noted that whilst the ladder model could present as a linear hierarchy with the top being 'best', this is not always the case. Movement does not have to be sequential, and one action may result in a shifting up (or down) several rungs on the ladder (Greater London Alcohol and Drug Alliance, 2005).

Common arguments against consumer participation

Drug users don't know what's in their best interests. Professionals do.

Staff and consumer attitudes are a key determinant and require a long term process of cultural change reinforced through awareness raising, training, supervision and mentoring. (Hinton, 2010)

Clarke & Brindle (2010) suggest that both consumers and service providers can contribute to an 'us and them' view of the therapeutic relationship between service providers and consumers. It assumes a power imbalance, with the service provider holding most of the power, e.g. the potential to refuse service if people don't comply. However, the roles that are constructed – that of 'client' and 'professional' - can be seen as both unhelpful and artificial, with research identifying poor relationships between service users and staff as a principal barrier to the successful implementation of consumer participation (Rance & Treloar, 2015). Increasingly, expectations are that treatment services utilise the strengths-based approach that recognises clients as the experts in their own lives (McCashen, 2005), and that professionals should be guided by the client when drawing up Individual Treatment Plans (ITPs). Just as workers in the AOD sector come from a multitude of backgrounds with a diversity of experiences and skill sets, each consumer comes with a unique history and set of experiences. The artificial divide of 'us'

and 'them' ignores the diversity of the individuals contained within these artificial groupings (AIVL, 2011; Hinton 2010), and stronger consumer participation not only challenges the 'them and us' treatment divide, but validates the consumer in a number of ways;

For service users, the opportunity to have 'a voice' began to disrupt the routine objectification or dehumanisation that consistently, if unintentionally, characterises the treatment experience. Having a voice, it seemed, was synonymous with being human, with having ones' 'humanness' recognised. (Rance & Treloar, 2015)

How can staff and consumers work together? Surely there's a conflict of interests?

The perception of competing interests can be seen as a misconception; however, fear is a factor that can influence both consumers and service providers (Clarke & Brindle, 2010). Professional workers may feel resentful as their knowledge and expertise is being questioned, whilst consumers may feel that their treatment may be affected or even withdrawn if they make negative remarks. Alternatively, consumers may simply feel that they will make a fool of themselves (Clarke & Brindle, 2010), or that they will be perceived by other consumers as having a 'foot in both camps', and being in collusion with staff (Bryant et al, 2008^b). It is important to be clear that consumer input is not meant to override or supplant professional roles and knowledge, rather that they will be working together in a complementary manner in a process of collaborative or shared decision-making (Bryant et al, 2008^a).

Overcoming drug dependence is hard enough. We shouldn't be putting an additional burden of expectation on people who are already struggling.

This assumes that clients of AOD services lack the skills and agency necessary for meaningful participation, and that they are somehow 'lacking', a view often perpetuated by western models of medicine (Bryant et al, 2008^b). Consumers are a diverse group with a wide range of skills and experience, and there are many examples of consumer-led initiatives that have been successful (Greater London Alcohol and Drug Alliance, 2005). Research has found that increasing client involvement in decision making about their own treatment leads to significantly better improvements (Joosten et al, 2009).

Consumers are not forced to participate in their AOD service, but if they choose to do so can be given a number of different options regarding their level of participation (see model of consumer participation above). Certainly, consumers should not be expected to participate without appropriate support and, where needed, training (Bryant et al, 2008^a).

Providing AOD treatment is hard enough. Adding consumer participation just adds another burden on already overstretched services.

Whilst the AOD treatment system in Australia is undeniably under-resourced (Rance & Treloar, 2015), AVIL (2011) suggest that many perceived problems of organisational capacity for consumer participation are in fact associated with an overall lack of philosophical support and resourcing for consumer participation. For consumer participation to be successful, it needs to be considered 'core business' by the AOD sector, and be funded accordingly.

It's just tokenistic. Clients will never have any real power.

The process of increasing levels of consumer participation is in the early stages in the AOD sector. By comparison, the mental health sector has a well-established system of sector-wide consumer participation, where it is viewed as a 'mainstream expectation and practice', and where consumer-led reform has been described as a 'keystone in the implementation of the national mental health strategy (Victorian Government, 2009^b).

The development of a policy framework at both sector-wide and service-wide levels would ensure agencies were supported to implement a model of non-tokenistic consumer participation (AIVL, 2011).

Challenges and barriers to implementation and practice

There are a number of challenges and barriers to the implementation of consumer participation and poor implementation can lead to patchy and tokenistic practice (Hinton, 2010). These include:

Unclear aims, goals and responsibilities

Just as attitudes of consumers and service providers are central to the success of implementation, clear communication of aims, goals and responsibilities is also crucial. A 2011 pilot study of consumer participation across five different sites found that levels of awareness and understanding of consumer participation by the consumers themselves remained low throughout the project (AIVL, 2011). It is important that expectations and responsibilities are clearly articulated and understood by all parties. This can be assisted by involving consumers in developing terms of reference for consumer participation initiatives, and by building on existing initiatives by improving levels of communication between providers and consumers to ensure that consumers know about their opportunities to become involved (Bryant et al, 2008).

Stigma and discrimination

Many AOD treatment service users have experienced a great deal of stigma and discrimination, both in interactions with 'official' organisations (such as Government organisations and healthcare organisations) and in the wider community (Ti et al, 2012). Building an organisation's capacity to offer meaningful and beneficial consumer participation pathways will need to acknowledge the consumer's lived experiences and recognise that previous experience of discrimination within services may make it harder for them to engage with a service and trust their commitment to meaningful consumer participation.

How does it benefit the consumer to be involved?

Rather than just being seen as an exercise in 'ticking boxes', consideration needs to be given to the benefits for the consumer in the participation. There is a need for clear support structures, as well as consideration of the pathways into volunteering and/or employment; *'It should be about transforming lives rather than creating professional consumers'* (Hinton, 2010). It has been suggested that participation training should be offered to all consumers, not just those taking part in a particular consumer participation project (AIVL, 2011).

Consumer participation eligibility and representativeness

Consumers are not a single homogenous group; therefore consumer representatives need to represent the diversity of the group. Consumer participation initiatives should be able to represent: current and former consumers; family members; Aboriginal and Torres Strait Islander communities; culturally and linguistically diverse (CALD) communities; members of the gay, lesbian, bisexual, queer, transgender and intersex (GLBQTI) community; and other stakeholder groups. For this and other reasons, it would be optimal to have a representative group, rather than one or two individuals. It is also considered preferable that there be a transparent selection process (Clarke & Brindle, 2010).

Typically, eligibility tends to be based on consumer 'stability', but this can be difficult to define and so can serve as an arbitrary barrier to potential participants. Requirements relating to current AOD use (e.g. 'must be two years clean, must be completely abstinent') are considered unhelpful by some, with one participant in research by Hinton (2010) stating: *"As a service user rep you are asked to sign a drug user policy that is stricter than for workers and requires total abstinence"*. Alternatives include: being able to make a commitment to a set time or level of involvement, willingness to uphold agency

values/positions, and undertaking a transition plan (such as training and development) with the support of a mentor.

Confidentiality and privacy

AOD services, like any other health services, have clear policies relating to confidentiality and privacy, and there are often fears that these will be breached if consumers are involved in the organisation. This may not relate to them seeing client files, but rather overhearing conversations relating to other clients, or to personal information about staff. Consumer participants may also fear being identified as a drug user. However, AOD agencies are used to managing different levels of access to confidential information and it is not uncommon for some workers to have access to information about clients, whilst others do not. Like any other staff members, consumer participants can be educated about confidentiality and privacy, and good practice dictates that staff are mindful about what information they are disclosing in conversations around their workplaces (Clarke & Brindle, 2010).

Inadequate resourcing

Generally, AOD treatment service providers have not been funded for consumer participation by either State or Commonwealth funders, except for one-off projects (Clarke & Brindle, 2010, Bryant et al, 2008). A NSW survey by the Network of Alcohol and Other Drug Agencies (NADA, 2011) found over 70% of respondents identified funding as an area of support required to increase service user participation. Implementing a consumer participation model requires planning (Hinton, 2010), recruitment (Clarke & Brindle, 2010), training for both consumer participants and service providers (NADA, 2011), non-tokenistic remuneration for consumer participants (Clarke & Brindle, 2010), and ongoing expenses associated with evaluation (Hinton, 2010).

What is the best way to implement consumer participation?

Involving clients in services is not something to be undertaken lightly or hastily or simply because a policy directive demands it. It requires the building of relationships and trust. (Clarke & Brindle, 2010)

Clarke & Brindle emphasise the importance of any consumer participation initiatives providing meaningful outcomes for participants. They must be useful to consumers if they are to be effective. For this to occur there should be a focus on process and relationship-building to ensure shared ownership of the outcomes and promote further development. They outline the following principles of meaningful participation:

- **Timelines:** outline the phasing of consumer participation implementation, decision making processes and key implementation dates from the outset.
- **Honesty:** provide consumers with a realistic expectation of the extent to which their participation will affect the final result. Don't include consumers if there is no chance of their ideas being incorporated. Tokenistic initiatives will be detrimental to all parties.
- **Inclusiveness:** seek to achieve as representative a cross-section of consumers as possible and avoid relying on a small number of 'hand-picked' representatives. This will help to avoid skewing consumer input to particular groups and help promote transparency.
- **User friendliness:** initiatives must be easily accessible and consider consumers' needs. Reduce jargon and don't expect consumers to have time to read extensive background documents.
- **Respectfulness:** consumers need to feel heard, regardless of whether the feedback they are providing is relevant. Initiatives should demonstrate a level of care for participants that are consistent with clinical services.
- **Remuneration:** participants' time should be valued and associated costs covered (as a minimum).

- **Training and support:** participants should receive appropriate training and ongoing support in order to carry out higher level roles such as steering groups, selection panels or group facilitation.

Summary

There is clear evidence to support involving consumers in a meaningful way that benefits both the service and the consumer. Consumer participation should be a standard component of all AOD treatment services, and there are now National and State frameworks to support the implementation of consumer participation. However, significant investment in this area is needed to embed best practice consumer participation practices across the AOD treatment sector.

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About ReGen

Our purpose is to promote health and reduce alcohol and other drug related harm.

ReGen is the lead Alcohol and Other Drugs (AOD) treatment and education agency of UnitingCare Victoria and Tasmania. ReGen is a not-for-profit agency, which has over 45 years' experience delivering a comprehensive range of AOD treatment and education services to the community.

These services include Counselling and Support, Assessment and Intake, Community Outpatient, Home-based and Residential Withdrawal for adults and youth, Supported Accommodation, Drug Diversion programs, Youth and Family Services, an Intensive Playgroup, Alcohol Community Rehabilitation Program and AOD services at Port Phillip Prison. ReGen also delivers Education and Training programs nationally.

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