“Straight from the Source”

A practical guide to consumer participation in the Victorian alcohol and other drug sector

Second Edition

APSU
ASSOCIATION OF
PARTICIPATING SERVICE USERS

The Association of Participating Service Users
A service area of the Self Help Addiction Resource Centre

sharc
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Acknowledgements

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ASSOCIATION OF PARTICIPATING SERVICE USERS (APSU)

The Association of Participating Service Users (APSU) is a Victorian consumer representative body at the Self Help Addiction Resource Centre (SHARC). APSU believes that people who use alcohol and other drug (AOD) services have a wealth of knowledge and experience.

APSU works to ensure that the opinions, ideas and experiences of the people who use alcohol and other drug services contribute to policy, research, service provision and professional development. APSU draws guidance and direction from an advisory committee made up mostly of consumers. APSU undertakes research, develops and disseminates written information materials and newsletters, and facilitates consumer participation.

APSU's Vision

A supportive and inclusive democratic society where people impacted by drug dependency are treated with respect and dignity, free of stigma and discrimination, and where their needs, strengths and expertise inform and drive the Alcohol and Other Drug (AOD) service system, policy and research.

Our Mission

To ensure the voices, opinions and experience of consumers are heard, respected and integrated into service and policy development by:

- Training consumers to develop the skills they need to be involved in participation and other lived experience activities within the AOD sector.
- Working with key stakeholders to increase consumer impact on relevant policy development and implementation at the local, state and national levels.
- Building capacity within the AOD sector to support and promote consumer involvement in the design and delivery of services
- Advocating and creating opportunities for systemic change on behalf of AOD consumers to better meet their needs and improve their quality of life.

APSU's membership is free and both consumers and service providers are encouraged to join via www.apsuonline.org.au

SELF HELP ADDICTION RESOURCE CENTRE (SHARC)

SHARC, a community based, not for profit, incorporated organisation, is a peer-based service made up of a combination of people with lived experience and professional expertise. SHARC provides housing, education, advocacy and family support to members of the community who have been affected by alcohol and other drug use.

SHARC's mission is to provide opportunities for individuals, families and communities affected by addiction and related problems to recover and achieve meaningful, satisfying and contributing lives. SHARC provides models of practice for family support, consumer participation and peer-based recovery support; and influences practice in the field of addiction and other related health domains.

A word from the SHARC CEO

This is an exciting period in consumer participation in the AOD sector, with many organisations having incorporated consumer participation into their organisation frameworks.

It is critical that we, as services, continue to seek, engage and respond to the information offered by consumers and include their voice in all levels of service delivery, organisational functioning and policy development

We hope this second edition of “*Straight from the Source*” (which also includes family members) reflects where the sector benchmark sits now, with some inspiration and guidance to keep moving forward.

We offer you our encouragement, support and opportunity for mutual learning as we travel this rich and rewarding journey together.

Heather Pickard.

Heather Pickard
Chief Executive Officer at SHARC

Introduction

There has been considerable effort and success on the part of AOD services in developing consumer participation practices within the sector. Historically consumer participation in the AOD sector has lagged behind that of the health and mental health arenas, but this situation is improving, especially as the sectors work more closely together.

The Victorian Department of Health and Human Services (DHHS) regularly includes consumer participation statements in its policy documents. There are now more resources available to inform and support consumer participation activities. APSU has delivered consumer participation training to many diverse groups and stakeholders.

Straight from the Source draws on literature, input from consumers and service provider focus groups, and APSU's own experience in conducting consumer participation activities, to provide a comprehensive guide to participation in the AOD sector. APSU has sought not only to gather the theory of consumer participation in the AOD sector, but also the practice.

The first section is a discussion on consumer participation and how it can be applied to the sector. The second section includes a consumer participation plan for organisations and the third section contains an extensive range of real life examples of participation activities across AOD services, training, policy development and research.

This guide is written solely by consumers. It conveys experientially validated approaches to engaging with service users and their families to produce meaningful consumer participation.

APSU anticipates that this handbook will be used by the AOD sector in the development and implementation of significant, meaningful and sustainable consumer participation.

How to use this handbook

Straight from the Source was written in the knowledge that despite its importance, most service providers have little time and resources to dedicate to consumer participation.

It is intended to be a reference guide that can be easily read or browsed through quickly. There are therefore several ways to use this handbook:

- Read through in chronological order
- Choose a topic of interest from the contents page
- For ideas on how to move forward in your organisation, look at Part Two: A plan for organisations
- Select practical strategies and examples you are interested in from Part Three

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Definitions

The language used to describe people can sometimes be problematic. For example, a patient is someone who sees a doctor, a client is someone who needs help and a consumer is someone who purchases products from the free market.

These are the definitions used for this handbook:

CONSUMER

A consumer is someone who uses, has used, or is eligible to use AOD services. It includes those people who are refused services or who refuse services. It also includes family, friends and significant others of people who use services, regardless of whether or not they directly use these services themselves. People affected by AOD policy and laws are also considered consumers.

The word ‘consumer’ in this document may also occasionally be used in relation to the use of other health and community services.

SERVICE USER

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

CLIENT

A client is a person who uses or has used a particular or specific alcohol and other drug service.

FAMILY MEMBER

The word ‘family’ or ‘family member’ or ‘significant other’ is used to describe parents, children, siblings, partners, carers or friends. For every person who experiences problematic alcohol or other drug use, there are at least two close family members who may be significantly affected by their behaviour. (Effective Interventions Unit, 2002)

The exact number of family members, carers and significant others affected by drug use cannot be identified. However, the impact of any one individual’s drug use can spread widely from family members to the wider community as a whole.

Family members are considered consumers. If a person is in treatment, their family can also be considered service users. If a family member receives treatment (e.g. counselling) from a service, they are also a client.

CONSUMER PARTICIPATION

Consumer participation is broadly defined as 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. (Bryant et al., 2008a)

Consumer participation in the AOD sector consists of including consumers (as defined above) in the decision-making processes around:

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

SERVICE USER PARTICIPATION

Service user participation involves alcohol and other drug service users making decisions about their own treatment, services, research, education and policy. Service user participation is the same as consumer participation, except that it does not seek to involve people who don't use services or who don't use a particular service. This term is used occasionally in this handbook.

FAMILY PARTICIPATION

The process of family participation is essentially the same as that of consumer participation, but is specific to inclusion of family members in decision-making processes around AOD treatment, policy and education.

Family participation can, and sometimes should, occur separately from service user participation. An important element of distinction between these two processes is entailed by the complex nature of AOD issues. Family members can be supportive of a person with a drug issue, but they can also have conflicting feelings about their behaviour. These complexities demand that family participation is given a degree of separate attention from service user participation.

REPRESENTATIVE

A representative is a consumer who is nominated by and accountable to an organisation of consumers. The term 'representative' is linked to democracy. The representative represents the formal views of a particular group and reports back to that group. (Victorian Department of Human Services, 2006)

Unfortunately, formal consumer representation in the AOD sector is often not possible as there are very few consumer organisations and groups that can nominate representatives and receive their feedback. Therefore, it is most common that a representative in the AOD sector has informal links to other consumers or is able, by virtue of their experience or training, to represent a broad consumer perspective.

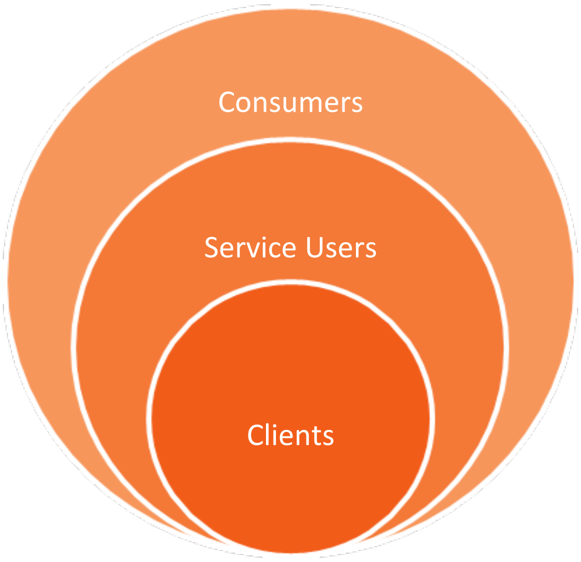


Figure 1: Relationship between consumers, service users and clients

PART ONE:

Consumer participation in the alcohol and other drug sector

BACKGROUND

Background

HISTORY

It is difficult to trace the beginnings of consumer participation. Certainly, it has its origins in community or citizen participation, human rights and participatory democracy. However, there is probably no identifiable starting point.

As early as the late 1800s, women, who came to be known as suffragettes, began their self-led campaign to gain the vote. Women all over the western world decided that they would have their say in electing governments that made decisions that affected their lives. This was followed in the 1960s and 70s with the black civil rights movement, the anti-Vietnam protests, gay rights and women's movements (Rubin, 1969). All of these campaigns were led by the people who would be most affected by the changes they sought.

The 60s and 70s also saw the emergence of citizen participation in housing developments, particularly those that affected impoverished communities (Rubin, 1969). The US introduced legislation that required 'maximum feasible participation of the poor' in Department of Housing and Urban Development programs. Closer to home in Sydney, resident action groups were formed in response to proposed housing development projects (Rubin, 1969). Third world countries also benefitted from a shift in thinking, from centralised control of projects to an inclusion of local knowledge in the planning process (Rubin, 1969).

> **"People have the right and duty to participate individually and collectively in the planning and implementation of their health care."**

This movement of people demanding to have a say in the things that affect them began in the health sector at around the same time. In the late 1960s, the US passed a law stating that agencies, including mental health centres, should have advisory councils that included consumer representatives (Cowling, Edan, Cuff, Armitage & Herszberg, 2006). In 1978, the World Health Organization declared that, People have the right and duty to participate individually and collectively in the planning and implementation of their health care. (Declaration of Alma-Ata, 1978) More locally, the Whitlam government in 1973 launched its Community Health Program with community health centres controlled by the 'local community' (Rubin, 1969). The western world was beginning to recognise that the way to have the best services and improve health outcomes was to seek the input of people using the services.

In Australia in 1985, after a delegation of community representatives presented a submission to the Commonwealth Minister for Health, the Consumers' Health Forum was set up. The 1993 National Mental Health Strategy 'recognised the importance of health consumers being more actively involved in their own health care' as well as 'having a broader role in health service development' (Johnson & Silburn, 2000). In 1995, after a study found that 8% of hospital admissions experienced an adverse event which could have been avoided, a taskforce for quality control was formed. This led to the formation of the Consumer Focus Collaboration in 1997 (Johnson & Silburn, 2000). This national body, made up of consumers and professionals, is responsible for strengthening consumer input in all aspects of health care (Consumer Focus Collaboration, 2001). The Health Issues Centre, operating in Victoria, has fulfilled a similar role since 1985.

Consumer participation in the mental health and AOD sectors occurred very early with self-help groups (Mills, 2006). Alcoholics Anonymous began in the US in the 1930s and there are now estimated to be 18,000 members in Australia (Alcoholics Anonymous Australia website). Similarly, Grow, a mutual help twelve-step group for those affected by mental health issues, began in 1957 in Australia and is still thriving today.

More formal participation in mental health services began as a response to pervasive negative experiences of the psychiatric system. The consumer body Victorian Mental Illness Awareness Council (VMIAC) was established in 1982 and funded in 1988. The landmark Understanding and Involvement research project, (Epstein & Wadsworth, 1994) conducted by VMIAC in the early 90s, was an evaluation of inpatient treatment practices in a Royal Park psychiatric ward. The study included equal input from consumers and staff and eventually led to the Victorian Government funding consumer consultants in all areas of mental health services in Victoria (Department of Health, 2013). Nationally, federal health ministers endorsed the national Mental Health Statement of Rights and Responsibilities in 1991. These rights included 'participation in decision making regarding the development of mental health policy, provision of mental health care and representation of mental health consumer interests (Stacey & Herron, 2002).

The Report of the National Inquiry into the Human rights of People with Mental Illness, aka The Burdekin Report (Human Rights and Equal Opportunity Commission, 1993), was also fundamental in the development of mental health consumer participation.

Possibly for the first time, individual experiential accounts were treated as facts, worthy of recording along with the rest of the evidence (Epstein, 2005). The first National Mental Health Strategy (also 1993) had a strong emphasis on consumer participation and led to the development of the National Community Advisory Group on Mental Health (and similar state groups), which reported directly to the Commonwealth Minister for Health. Consumer participation in mental health had become firmly established, although it still had a long way to go.

The AOD sector is perhaps the last area of health care to include formal consumer participation. After the emergence of self-help groups came the drug user groups. The Australian Intravenous League (AIVL) and its Victorian counterpart, VIVAIDS (now Harm Reduction Victoria), were formed in the late 80s in response to an increased awareness of HIV/AIDS and received official funding ten years later. These advocacy bodies are peer- based organisations that seek to protect the rights and the health of illicit substance users.

Consumer participation in the AOD sector began to appear in policy documents in the late 90s. In 2000, APSU was established with funding support from the Victorian Department of Health and commenced its work to increase consumer participation across the Victorian AOD sector.

In 2006 the Victorian Government issued the policy document *Doing it with us not for us* (Victorian Department of Human Services, 2006), which outlined the necessity and importance of consumer participation in the Victorian health services. Although *Doing it with us not for us* does not speak specifically about complexities of the AOD context, it provided a basis for consumer participation across the health sector.

CONSUMER PARTICIPATION IN THE ALCOHOL AND OTHER DRUG SECTOR

Participation as a right

Consumer participation is an ethical and democratic right (Victorian Department of Human Services, 2006). We live in a democracy where we are entitled to vote, however, this in itself is not enough. As citizens, we need to have a say by actively participating in the policies and processes that affect the most important things in our lives such as housing, education, health care and employment. All of us need to be given a choice about voicing our opinions on decisions that are made, especially if these decisions have a direct impact on us and the way we live.

Participation as accountability

Consumer participation ensures public accountability. With no input from service users, regardless of evaluation or accreditation, there is no knowing if the consumer is satisfied with the service provided.

Participation strengthens the accountability of institutions by involving individuals directly in decision-making around issues that affect them.

Participation as policy

Gradually AOD consumer participation is becoming embedded in sector policy.

Victorian AOD policy is framed in terms of having a 'client- centred' or 'client- focused' service system. In 2008, the Victorian Government issued *A new blueprint for alcohol and other drug treatment services 2009-2013* (Victorian Department of Human Services, 2008b), which provided a vision for future development of the AOD service system. The policy stressed the need for a system that is 'client-centred' and 'service-focused', and envisioned 'stronger client and family involvement in service planning and development' as one of the ways to achieve this.

This was further reinforced in Victoria with the publication of *Shaping the future: the Victorian alcohol and other drug quality framework* (Victorian Department of Human Services, 2008a). This document outlined six quality standards for the AOD sector. The first standard was *Consumer focus*, which recognised that consumer participation is a critical component of a client-centered service system.

Dual diagnosis: key directions and priorities for service development (Victorian Department of Human Services, 2007), documented the five main outcomes to be achieved by the mental health and AOD sectors in order to make both sectors more capable in responding to people with dual diagnosis. It recognised that a major involvement of consumers and carers is needed in the planning and evaluation of the services.

The Victorian Government, in collaboration with the AOD sector and consumers, developed a set of Victorian AOD treatment principles, published in 2013. The ninth principle provided the important ground for consumer participation: 'The lived experience of alcohol and drug consumers and their families is embedded at all levels of the alcohol and other drug treatment system (Department of Health, 2013).

The 2011 Victorian Auditor General's Office (VAGO) report on AOD treatment services was highly critical of the AOD treatment system (VAGO, 2011), including the failure to include service users and family members in the governance and coordination of reforms that followed the *Blueprint*. The VAGO report triggered the AOD sector reform, which was presented in the *New directions for alcohol and drug treatment services: A roadmap* (Department of Health, 2012a). This stated that the AOD sector reform was moving towards a person-centred family-inclusive and recovery-oriented system. The person-centered component was defined as a system of 'services [that] work with clients rather than doing things to them', whereas family-inclusive referred to inclusion of family members in treatment and provision of better information and support for families.

Current Victorian AOD program guidelines detail key service requirements which include encouraging and considering consumer feedback across key aspects of service planning and delivery (Victorian Department of Health and Human Services, 2018a), by relying 'on a strong consumer focus, encompassing consumer involvement in the planning and review of treatment and service accessibility'.

Services should 'recognise and respond to consumer rights and responsibilities, actively encourage genuine and meaningful consumer participation, and use consumer feedback in the planning, development and delivery of services, programs and interventions' (Victorian Department of Health and Human Services, 2018b).

The Commonwealth Government also defines consumer participation and its role in drug treatment services on consumer participation (Australian Government Department of Health, 2011).

Consumer participation is also a feature of quality assurance and accreditation for AOD services. The Quality Improvement Council Australia Health and Community services standard has a specific standard relating to participation stating that " people's right to choice, decision making and to actively participate as a valued member of their chosen community is promoted and upheld (Victorian Department of Health and Human Services, 2018d).

Victoria's *Community Services Quality Governance Framework* identifies the role and rights of clients and families in ensuring quality and good governance of community services including AOD (Victorian Department of Health and Human Services, 2018c).

Participation as a process

Involving clients in services is not something to be undertaken lightly, hastily or simply because a policy directive demands it. It requires the building of relationships and trust. In order for consumer participation to be meaningful it needs to fit in with other existing processes in an organisation or a system. If it sits outside other processes, it cannot truly have an impact. The possibility, or even likelihood, of changing other organisational processes and ultimately the organisational culture, must be supported by the management and embedded within the process of consumer participation. It follows that the form of consumer participation processes will depend on the individual setup of each organisation, as they depend on other processes of organisational decision-making.

APSU acknowledges that some AOD agencies may find it difficult to meaningfully engage their consumers, especially at medium to high levels - see *Levels of participation*. However, participation is a process and organisations can aim to increase consumer participation gradually and sustainably over a period of time.

Consumer participation needs to be built as a relationship of equals between consumers and service providers, with open dialogue where each participant is respectful of others and everyone has the opportunity to express themselves. Trust between consumers and service providers needs to be developed and cultivated. Good communication and information flow are essential to achieve this.

A set of key principles developed by South Australia's Consumer Focus Collaboration is most useful here:

1. Participation means partnership, means accepting uncertainty.
2. Deciding for effective consumer participation means deciding for organisational change.
3. Align your consumer involvement plans with organisational capacity. Involve staff in building that capacity.
4. Consumer participation must be supported from the top down, but it is built from the bottom up.
5. It's all about relationships, so use and build people skills.
6. Consumer participation needs partnerships, partnerships need dialogue, dialogue needs trust. So build trust.
7. Multiple strategies work better (Consumer Focus Collaboration, 2000).

The aim is to ensure:

- consumers and their unique needs are key organisational priorities
- consumers are actively invited and supported to provide feedback on their experiences
- consumers are provided with the relevant skills and knowledge to participate fully in their service provision to the extent they wish
- consumers are provided with the opportunity, information and training to fully participate in organisational processes for planning, monitoring and improving services
- clear, open and respectful communication exists between clients and staff at all levels of the service
- services respond to the diverse needs of consumers and the community
- services learn from and act on consumer feedback on service delivery to make improvements
- consumer participation processes are monitored for their effectiveness

- complaints are responded to compassionately, competently and in a timely fashion, with feedback provided to all parties about the action resulting from their input
- issues arising from complaints are analysed, reported and used to improve services
- consumers' rights and responsibilities are respected and promoted
- consumers are made aware of oversight bodies available to assist and advocate for them.

Participation as an instrument of social inclusion

Social exclusion comes with a range of complexities, which are hard to solve exactly because those that are excluded are outside of social, political, cultural and economic processes (Cappo & Verity, 2014). Social isolation and the feeling of not being heard are commonly part of this experience (Peel, 2003). People experiencing social exclusion are often left out of decision-making processes that relate to issues directly impacting upon them (Dibben, 2006). Being provided with an opportunity to participate is particularly important for AOD consumers, because their voices are rarely heard in any other political arena.

Empowerment is essential for democracy and health. Empowered communities are healthy communities. The ability to have an understanding and control over various forces that impact one's life, including the ability to influence decisions of institutions, is central to empowerment. Therefore, participation can be an indicator of health in a community or organization (Bush & Baum, 2001).

Participation is conducive to building and strengthening social capital. Social capital refers to social networks, relations, support and trust within the community, and the lack of it is closely associated with health inequality (Germov, 2009). A strong social capital base is an indicator of a healthy, connected and inclusive community (Baum, Parker, Modra, Murray & Bush, 2000).

EVIDENCE

The Consumer Focus Collaboration has played an important role in consumer participation in health service planning and delivery at a national level since 1997. The Collaboration states (Consumer Focus Collaboration, 2001) that:

- Active consumer participation in decision-making in individual care leads to improvements in health care.
- Access to quality information facilitates decision-making and supports an active role for consumers in managing their own health.
- Active consumer participation leads to more accessible and effective health services.
- Effective consumer participation in quality improvement and service development activities in health services is achieved through a range of methods.
- Effective consumer participation uses methods that facilitate participation by those traditionally marginalised by mainstream health services.
- Active involvement of consumers at all levels of the development, implementation and evaluation of health strategies and programs is integral to their success.

The first two statements are the most supported by solid evidence (Victorian Alcohol and Drug Association, 2010; Lorig, et al., 1999; Gibson, et al., 1998). Unfortunately, a lack of research in the area of consumer participation has led to a lack of quantitative support for the remaining statements (Crawford, et al., 2002).

While randomised controlled trials are seen as the ‘gold standard’, we must not ignore other types of evidence nor refuse to change our practices until more quantitative data is available. Qualitative research including anecdotal, expert and experiential evidence is also valid (Langlois et al, 2018) and many of the advances in society would not have occurred without it. Qualitative data supporting the benefits of consumer participation in health, mental health, homelessness services and the alcohol and other drug sector exists in the form of participatory research results, case studies and anecdotal accounts (Pinches, 2004; Simpson & House, 2002). APSU has seen some of these benefits first hand.

In 2014 the Australian National Council on Drugs (ANCD) hosted a round table meeting of key stakeholders to explore consumer participation in the drug and alcohol sector.

Nine key issues that emerged were:

- Consumer participation generally, and in AOD services specifically, is both a consumer right and an ethical imperative.
- The diversity of the sector - of consumer’s service agencies and intervention modalities - has significant implications for patterns of participation.
- The need to build on past experience of consumer participation and to better disperse examples of good practice.
- There is a pressing need for more and better quality research into the contribution of consumer participation in AOD services.
- Consumer participation is largely absent from national and state/territory AOD policy documents.
- Participatory processes should be embedded in ongoing governance of agencies.
- Consumer participation does not work without strong commitment by management and accompanying resources.
- The contributions of families and carers warrant specific attention rather than being subsumed in wider discussion of participation.
- Among the barriers, the most important and challenging relate to concerns about the impacts of high-level consumer participation on staff confidentiality.

This article appeared in the *Of Substance Magazine, vol. 12 no. 1, March 2015*

BENEFITS

Much of the material below is adapted from the *Consumer Participation Resource Kit for housing and homelessness assistance services* (HomeGround Services and Rural Housing Network LTD, 2008).

Quotes, unless otherwise stated, come from the service user, family or provider focus groups or consultations conducted by APSU in the development of this guide.

Benefits to organisations

- Consumers who feel they have a say are more likely to be positive about new proposals and strategies or changes to existing services if they are involved in the planning process. A feeling of ownership creates greater cooperation between the consumer and the service provider.
- Consumer participation improves understanding of the existing needs within the community, which leads to increased efficiency in service delivery.
- Consumers are a (largely) untapped resource who are able to contribute to the growth of an organisation by providing feedback on programs, as well as offer solutions or answers to problems.
- Consumers may develop a better understanding about the connection between funding and services and may be less likely to express resentment and suspicion of how resources are applied.
- Trust is built between service users and staff.
- As services improve through the use of consumer participation, staff experience greater job satisfaction.
- Clients learn the value of peer support

Benefits to consumers

A better service system

- Higher quality services that are more responsive to consumer needs.
- A service system that is more sensitised to the service users' right to be there, to be heard and to hear how decisions that affect them are made.

Empowerment and psychological wellbeing

- As service users engage in the participation process they are more able to express their dissatisfaction with services and offer solutions or ideas for improvement.
- Disengagement from a particular service is less likely if a service user is given the chance to voice concerns.
- Listening to and valuing a person's experiences and knowledge promotes self-esteem. This is a particularly positive outcome for people who use AOD services and may be carrying the shame and stigma of their drug use.
- Participation changes a person's position from that of always needing help to being able to contribute and help others.
- Overcomes the sense of powerlessness that is frequently felt by individuals and communities.
- A sense of empowerment contributes to the person's own recovery process (Consumer Focus Collaboration, 2000). In fact, the very act of participating improves recovery outcomes.

> “It’s the realisation that the knowledge you have is useful... that you haven’t just wasted 10-20 years of your life on drugs. You’ve actually had valuable experiences that can be used for something else” - Service user

Skills and confidence

- Involvement and participation connects people. It provides support and promotes networking and friendship among peers, workers and policy makers.
- Participating individuals gain satisfaction from influencing change in their immediate environment (Brodie, Cowling & Nissen, 2009)
- Service users may gain skills in areas such as how to run meetings, communicate ideas, make decisions, deal with conflict and gain support for a cause. These skills can be transferred to a person’s wider life and may ultimately lead to employment.

“I go from being the hopeless drug addict to being more useful to myself, having more respect for myself” -Service user

The wider community

- Consumer participation in publically funded organisations provides opportunities for participation in democratic decision-making. This can build the capacity of service users to engage as active citizens in other arenas.
- Participation creates healthier and better connected communities.
- Participation in decision-making at a local level empowers communities and builds social cohesion, as it gathers individuals around the issues of common interest.

“Holding positions of responsibility builds up my self-esteem and, you know, transforms [my] life in a way, getting back towards being a responsible member of the community” – Service user

BARRIERS

Attitudes of service providers

‘Us and them’

One of the biggest barriers to consumer participation in any field is the ‘us and them’ mentality held by workers, e.g. ‘we are the workers and they are the clients and we know what is best for them’. This divide between ‘professional’ and ‘client’ is artificial and unhelpful (Tyler, Pargament, & Gatz, 1983). Professionals take on a role when they are at work: the role of the expert, the helper, the fixer. This role is encouraged by the people who come to them for help and the very nature of the therapeutic services provided. The professional hat gives people a sense of power and a sense of being useful and able to make intelligent and informed contributions. It can also offer some protection against personal or professional insecurities.

When a professional leaves the workplace and encounters other professions, they are no longer the worker but the client. A doctor who has his car fixed is now the customer, the lawyer in need of medical help is now the patient and an AOD worker trying to resolve a complaint with a telephone company is now the consumer. Sometimes people will need to seek help from their own profession: a doctor gets sick, a lawyer has legal troubles and an AOD worker’s drug use gets out of control. The roles are reversed and power turns to powerlessness. When professionals refuse to acknowledge the contribution that patients, clients and consumers make, not only to their own wellbeing but also to the system that serves them, that powerlessness is reinforced.

> *“One of my best experiences is when they said… you don’t have to save me. This was an eye opener as I realised that I didn’t need to be everything” – Service provider*

Fear

Providers have worked hard to be in the roles they are in and to establish themselves in their chosen career, with specific education, expertise and skills related to their profession. Some workers may feel threatened when consumers are critical of their work practices or they offer advice and solutions to problems.

> *“The fear factor is the elephant in the room. Professionals are worried about their turf” – Service provider*

Providers may be fearful of change. For consumer participation to be meaningful, organisations must change as a result.

Providers may also be fearful of service users asking for things that cannot be delivered due to a lack of funding, resources or knowledge.

Lastly, providers may be fearful on behalf of their clients. There is a concern that vulnerable service users could become distressed by the consumer participation process.

Belief

Providers may not believe that service users can contribute or may not be able to contribute effectively because of the lifestyle that often accompanies drug use.

Representation issues

The issue of adequate representation is often raised regarding consumer participation. The concern is that any one person cannot adequately represent the diverse community affected by AOD issues. An effort should be made to include people from diverse backgrounds in both service user and family participation. Nevertheless it is likely that some views will be missing. The issue of representation is best addressed through training and education, such as that provided by APSU.

“People are at management level and at times I feel like a bit of a kid” - Service user

Attitudes of consumers

‘Us and them’

Consumers may also perpetuate the ‘us and them’ stereotype.

Fear

Service users may fear that their treatment will be affected or even withdrawn if they give negative feedback to AOD services.

They may be frightened of speaking their mind in front of professionals for fear of making fools of themselves or not being taken seriously. Often, the higher the level of participation, the greater the fear of failure.

Belief

Consumers may believe they have nothing to contribute or that it is too difficult to contribute in the types of forums offered. Others believe that it is ‘not their place’ to get involved or that they ‘just want treatment’, they don’t want to be part of the decision making process (Bryant, Saxton, Madden, Bath, & Robinson, 2008b).

Consumers may also believe that they won’t be listened to and that if they do provide feedback, nothing will change. Negative past experiences may need to be addressed by the organisation before new participation opportunities are created.

Discussion on attitudes

The Treatment Service User (TSU) project (Australian Government Department of Health, 2011) researched the attitudes of both service providers and service users towards consumer participation. Providers’ and service users’ views were remarkably similar in many aspects, e.g. that ‘service quality would be improved if clients’ opinions about services were included’ (84% and 89% respectively), that ‘client representatives should be included on committees that decide how services should be run’ (72% and 87%) and that ‘services should hold open meetings to get clients’ views on how the service should be run’ (79% and 85%). This demonstrates overwhelming support for the principle of consumer participation from both service providers and service users of the AOD service sector. Both providers and service users were more willing to be involved in lower level activities than higher levels.

The biggest difference in provider and service user attitudes was evident in the type of participation activity a provider or consumer said they would be willing to take part in. While both providers and service users would be similarly willing to participate in suggestion boxes, surveys, service user councils or forums (82/87%, 89/89%, 60/68% respectively), providers, compared to service users, showed a great reluctance to have consumers involved in staff recruitment, training or appraisal.

Overall, the TSU project demonstrated that ‘consumers and providers of Australian drug treatment services were strongly in favour of incorporating consumers’ views into the process of service planning and delivery’.

Training

There are many and varied methods of participation as well as ways of addressing barriers and increasing the likelihood of meaningful participation.

Most consumers have not been trained. There is a big gap between receiving treatment and understanding the structure and processes of an organisation, its policy, planning and resources. Consumers can be educated in understanding jargon, meeting formats, funding arrangements and organisational processes so as to provide meaningful input. Providers can help by using everyday language and being flexible in their approach.

Even with appropriate training it may still be difficult to know where to start. This handbook includes a section on how organisations can get started on increasing their consumer participation (see *Part Two: A plan for organisations*).

Resources

Development of consumer participation requires time and other resources. It is often a challenge for organisations to identify adequate resources and funding to support consumer participation. However, increasingly funding bodies are expecting consumer participation to be an integrated part of service provision and so should be adequately budgeted for at tender and application stage.

Consumers can also suffer from a lack of resources. Some service users are so consumed with attending to their own treatment needs that there is nothing left to give. Sometimes issues are of a more practical nature, for example transport or babysitting. These issues can be taken into consideration when planning consumer participation opportunities.

Confidentiality and privacy

Providers may fear that confidentiality may be breached if service users are involved. This may not relate directly to service users accessing client files but, for example, to staff conversations about clients or even personal information about staff themselves. This may be of particular concern to staff when service users become involved in staff selection. However, service users, like anyone else, can be educated about confidentiality and privacy, and staff need to be mindful when discussing confidential matters about clients.

Consumers, especially those who have been in 'recovery' for some time, may fear being identified as a drug user. While accessing treatment may be a relatively confidential process, participation opportunities may not offer the same level of privacy.

Confidentiality can be a tricky issue when service users become involved in participation. At agency level, some staff members know intimate details about a service user while others do not (and should not) and it is essential that client confidentiality is maintained by the worker directly involved in client care. If a staff member is concerned about a service user's ability to participate in a project or other aspects of a service user's welfare, this must be handled in a therapeutic situation, not in the participation setting.

Tokenism

Consumer participation is tokenistic when consumers' views do not have any real impact on the decision-making processes. This is usually a result of over-preparation (where the final decision has been made before involving consumers) or under-preparation (when consumers are not given sufficient information to be able to form an informed view on the question at hand) (Johnson, Lawn, & Struber, 2007). Tokenism is discouraging for consumers, as it reinforces the sense of powerlessness and devalues their lived experience.

Unfamiliar language

Like many other industries, AOD sector professionals have developed their own jargon. This helps communication between people who work within the sector, but excludes anyone who does not have an AOD professional background. Hence, the sector jargon can become a problem when discussing AOD issues with consumers.

Use of sector jargon and acronyms confuses consumers and is likely to create a sense of exclusion and inferiority. While it affects all consumers, family members are possibly more affected by this issue, because service users usually learn some jargon during their time in treatment. The language barrier can be neutralised if AOD professionals maintain an awareness of it and try to express themselves in simple, everyday language. Some AOD jargon and acronyms will still arise, so it is important to acknowledge this early in the participation process, and to encourage the consumers to ask for clarification whenever necessary. Training for consumers will also help with this issue.

Levels of participation

There are many models that describe community or consumer participation (Arnstein, 1969; Foroushani, Travaglia, Eikli, & Braithwaite, 2012). These models are useful for understanding the levels of power that consumers may have in different consumer participation activities. It is important to note that all levels of participation are necessary and valid.

Level of Power	Level	Description	Activities
High	Control	Consumers make all decisions and consumers have control of resources.	• Consumer-run organisations • Self help groups
Medium	Partnership	Consumers and providers are joint decision makers.	• Peer workers, educators, trainers • Staff selection panels • Steering committees
Low	Consultation	Consumers are presented with a plan or directive designed by the service provider and invited to give feedback. Control lies firmly with service providers.	• Suggestion boxes • Surveys • Focus groups • Service user groups
↑	Information	This is not consumer participation, but it increases power, enables service users to make decisions about their own treatment and supports consumer participation.	• Information to service users about services and treatment options • Charter of Rights • Complaints systems • Consumer participation policies

Table 1: Ladder of participation (Victorian Department of Human Services, 2006)

COMPLEXITIES AND LIMITATIONS OF THE LADDER

Table 1 is a simplified representation of consumer participation. It fails to convey the complexities of any given consumer participation activity. However, it is useful in its simplicity and ease of practical application and will be used in this handbook.

An activity fits into the ladder depending on the power of the consumer. The same activity may be classed as a higher or lower activity depending on how it is conducted. For example, a consumer representative on a staff selection panel with no voting rights would be a ‘consultation’ activity, while a consumer on the same panel with equal say in staff selection would be a ‘partnership’ activity.

Also, an activity may be considered to contain several levels of participation within the one project. For example, an idea from the suggestion box about creating a specific program is taken up (consultation), a consumer representative is part of a committee formed to plan the new program (partnership) and a subcommittee of service users is formed to create the promotional material for the program (control).

DOMAINS OF PARTICIPATION

Consumer participation in individual treatment and in organisations is not the only way that AOD service users can be involved. Education and training of professionals, research and policy development are the other areas that benefit from consumer participation. For the purpose of this handbook, these are referred to as ‘domains of participation’.

Figure 2: Domains of participation

Participation in any of these domains may be at low to high levels. For example, policy makers could invite service users to respond to a survey (consultation) about a proposed policy or to be part of the team drafting the policy (partnership).

Meaningful participation

Consumer participation in the alcohol and other drug sector is not just about ticking the boxes. Participation must be meaningful if it is to be at all useful. While engaging consumers in decision making about services, policy, education and research may be a difficult task, it can be done if service providers and professionals are willing to change their current work practices. Some of the guidelines that will ensure effective consumer participation are:

- Being clear about your organisation's capacity to involve service users and to respond to service user concerns.
- Being careful not to promise what you can't deliver.
- Consumer participation is only productive if it is supported by management at all levels.
- Effective consumer participation means that your organisation must be prepared to listen to feedback, make decisions and accept any changes.
- Enhanced consumer participation may mean that conflicts emerge and will need to be managed. This is okay and is likely to lead to better quality service and improved outcomes in the long term.
- Partnerships with service users are based on dialogue and trust. Trust is built by transparency and consistency.

> Service users are engaged early in the process - even in the process of deciding how your organisation will engage service users better.
>
> (Consumer Focus Collaboration, 2000).

PRINCIPLES AND PRACTICES

Adapted from HomeGround Services and Rural Housing Network Ltd, 2008.

Timeliness

Most consumer participation needs to occur in existing programs. However, for new projects, policy, education and research, it is essential to involve consumers before all the important decisions are made; if possible, right from the start. It is not meaningful to ask service users to make decisions about program details when they have not been asked what program(s) they would like developed in the first place. It is not meaningful enough to just include service users as respondents in research; consumers must also be involved in deciding the aims, content and structure of research projects.

Honesty

It is not honest to ask consumers what they think if there is no intention of implementing their ideas. There must be a feedback process for the input; it must go somewhere and have some effect. Be honest with consumers about the limits of their participation in changing the organisation, the project or the policy development. If consumers are only being consulted, they must be informed that their ideas may not be used. If they are only being informed, then be honest about that. Be realistic with any consumer participation process; don't include service users if there is no chance that their ideas will be included or if the organisation is unwilling to change. Tokenistic participation is detrimental to both client and staff morale.

Inclusiveness

A variety of consumer participation methods will produce the most ‘cross-sectional’ and comprehensive views. If possible, organisations should consider inviting new participants or representatives by using transparent selection methods for recruitment, not just selecting ‘the same old’ service users who are known to be agreeable.

User friendliness

When planning consumer participation activities, it is important to make opportunities accessible to service users. Use plain language in both written and verbal communication. Check with service users if you are not sure which words and phrases will be understood. When conducting meetings and forums, minimise the use of jargon and acronyms and explain all necessary terms.

Respectfulness

When consulted, consumers may not respond as desired. While the organisation may be interested in addressing a particular topic, the service user may be far more concerned about giving feedback on another, more pressing matter. Although it can be frustrating not to get the type of feedback you are looking for, see this as an opportunity to demonstrate to service users that you have heard them, rather than an opportunity to explain why you cannot do anything about their concerns. Inform service users of the avenues they can use to pursue other issues and offer assistance then return to your agenda. Often, people in user groups need to spend time airing their concerns about the abuses they have suffered as drug users – and justifiably so. When a group works through this, other work can begin, and the experiences and opinions can then be used in the planning and development of services.

Remuneration

Ideally, consumer participants should be remunerated. Many consumers participate for free, but it is important to recognise that a service user’s time and input should be valued just like that of a professional. The rate of financial remuneration varies between organisations. This may be a flat rate with additional remuneration for transport and other out of pocket expenses. It is important to plan for consumer participation expenses when creating budgets for new projects.

However, there are times when monetary payments are neither possible nor appropriate. Positions on a board of governance, committee of management or other long term committees that are an organisational fixture might not be remunerated. Such positions are considered as honorary, a means of building or furthering a professional reputation and as an opportunity for people to contribute to the community. Financial remuneration can be a barrier to the sustainability of a project. If there is a limited amount of money for a long term project then other forms of remuneration need to be considered.

Non-cash means of remuneration can be simply providing training and mentoring opportunities. This can prove to be advantageous for the service, region and sector when the outcome of training, support and mentoring of a service user leads to increased capacity. A service user who is trained and mentored can potentially become a leader and a means of gathering other interested service users, functioning as a chairperson on a committee, or supporting other service users as a peer. This may be a mutually beneficial arrangement between the service user and the service provider. Other examples of non-cash remuneration are:

- Assistance with seeking educational qualifications
- Certificates and references
- Letters of support in applying for a Working with Children Card
- Use of office equipment and available resources
- Mentoring to consolidate learning whilst participating

Consumer participation is not the same thing as volunteer work. Service users may be less well-resourced as volunteers and may require additional support while they are participating. Consumers should be informed whether they will be paid or not before they become involved in any activity.

The issue of using vouchers as payment can be problematic. Service users may find it demeaning, as it implies that they should not have the same freedom of choice in spending money as the rest of society. Professionals would not like to be paid in this fashion (APSU, 2017).

Training and support for consumers

For consumers to become involved in higher level participation roles, such as joining committees, facilitating service user groups, and contributing to staff selection, it is desirable that they receive proper training and support. APSU offers a series of consumer-based workshops called 'Experts by Experience' which cover topics such as: the AOD service system; AOD policy and advocacy; how to participate in meetings; and self-care for consumer participants. Other organisational based training may be relevant to the role performed. It may be possible to consider current staff training and induction processes and adapt them for consumer roles.

Consumer participants in medium to high level activities should be offered supervision as extra support. Supervision is best done independently of the relevant organisation for two reasons – organisations are not experts at consumer participation experiences and it may not be appropriate or easy for participants to discuss any concerns that arise with service staff.

Other issues to consider

Responder bias

It must be noted that as consumer participation is always a voluntary activity, there is an inherent risk of 'responder bias'. As most participation occurs with people who are using services, that is already a bias, with people who won't or don't use the service not being included in the process. People who respond to surveys and requests for other types of feedback possess certain skills and opinions that may not be shared by non-respondents. Participants who engage effectively in higher levels of participation, such as committee members, tend to have more confidence, initiative and personal resources.

Consumer participation is not an exact science and it doesn't pretend to be. It is not research; it is a dialogue. While attention should be paid to recruitment methods and strategies in order to provide the least biased and most inclusive responses possible, this must be balanced against practical concerns.

> "Often, people in user groups need to spend time airing their concerns about the abuses they have suffered as drug users – and justifiably so. When a group works through this, other work can begin – and the experiences and opinions can then be used in the planning and development of services"-Service user

Bias of paid consumer representatives

When a consumer is employed in a representative role in the AOD workforce, certain issues may arise. The representative may be reluctant to give negative feedback about their employer or they may only convey positive sentiments for fear of offending colleagues or funding bodies.

Workers from consumer organisations and consumer led services participating in policy development are aware of their dependence on government funding for their survival. This may have some influence on the input they provide.

If a service user is in 'recovery' and gains employment in the AOD sector, they may become somewhat removed from the day-to-day experience of the drug using lifestyle. It can sometimes be difficult to remember or relate to the immediate concerns and stigmatisation felt by current service users. Paid consumer representatives may also find that they are invited to voice their opinions more often now that they are in a paid role, and their opinions may not reflect the attitudes of other service users.

Evaluation

Evaluation begins at the inception of any project, with planning for evaluation a part of the overall plan of the project. A consumer participation project may start with consumer observation of the discrepancy (large or small) between what is expected and what is experienced (Wadsworth, 2011). For example, it may be deemed a problem that consumers are not involved in the selection of staff in an organisation that reportedly values consumer participation.

Indicators

Outcomes are also known as indicators. These are used to assess whether an organisation is achieving the goals of the project (HomeGround Services and Rural Housing Network Ltd. 2008). For example, a consumer who has been selected to participate in staff recruitment may be set the following indicators:

- The consumer will actively contribute to the discussion during the short-listing of applicants.
- The consumer will participate in the development of questions.
- The consumer will directly question the interviewee.
- The consumer will participate in post-interview discussion.

By establishing these indicators beforehand, service providers are not only clear about what is expected of participants, but have clear expectations that both parties can review and assess. Needless to say, it is an advantage if consumers are involved in the establishment of these indicators. This allows for greater accountability and interest in the project on the part of the consumer. For the service provider, it achieves the goal of ‘thinking out’ or finding out what others think (Wadsworth, 2011).

Fieldwork

In order to find out what consumers and colleagues think of a project, service providers need to develop methods of ‘immersing in their world’. Establishing an understanding as a result of observing, reading, listening and participating is just as important as ensuring that the collaborative process involves all parties who will be affected by the project outcomes. This means that conclusions are based upon what actually happened and not a single individual’s idea of what happened.

Tools

Establishing the appropriate evaluation tool is necessary during the planning stages. In fact, when writing a funding submission for a project, most often service providers will need to write how they plan to evaluate the project. The following tools may assist:

Focus groups

A group discussion held a month after the conclusion of a project gives more time for consumers to reflect on the effectiveness of their participation, and thereby give a more meaningful critique. People may be overly positive when filling out evaluation forms as they don’t want to offend, so it is important to prepare and establish the rules of engagement beforehand. Develop broad questions that will give people the space and understanding to raise an unexpected topic or question.

Feedback forms

Feedback forms are useful for data collection or gathering quotes to use in reports and presentations. Questions need to be worded carefully so as not to be too loaded with unnecessary jargon. Ensuring that each question is calling for different information is appreciated by respondents. Feedback might be sought at the immediate conclusion of a project, or evaluations can be done later over the phone. This allows time for people to reflect on how they found the project or training. Asking a person who has had no involvement in the project to conduct the evaluation may facilitate a more open and truthful response from participants.

Journal

Keeping a journal is a means of gathering qualitative material on a day-to-day basis. Include both verbal and non-verbal responses from people as these may assist with an assessment of the overall success of the project. It is essential to ask people's permission before undertaking such a process, as well as making it clear what you plan to do with the information. Structure the journal so that you respond to project goals.

Reports or reflective evaluations

Reflective evaluation happens naturally during a staff meeting when reporting on the progress of a project. The emphasis is on what has been learned and what can be improved. However, it is not enough to include a consumer participation project on the staff meeting agenda. It is also important to invite consumers who are participating in the project to be a part of this process. If this is not practical, a brief feedback meeting can be arranged separately as an opportunity for consumers to contribute.

Feedback to consumers and staff

Once a team has reflected on the results of the project, feedback should be provided to other consumers and colleagues. This gives service providers an opportunity to report their conclusions, review the project outcomes and allow consumers time to provide further comment.

Planning

Work practices and policies can now be improved or changed accordingly, and the process can inform future projects. According to Wadsworth, an evaluation involves researching other people's ideas of things (Wadsworth, 2011); time is taken to consider everyone's point of view and think about the changes that this will generate. The best evaluation provides direction on where to go next, whether it is to achieve the original objective or identify new objectives.

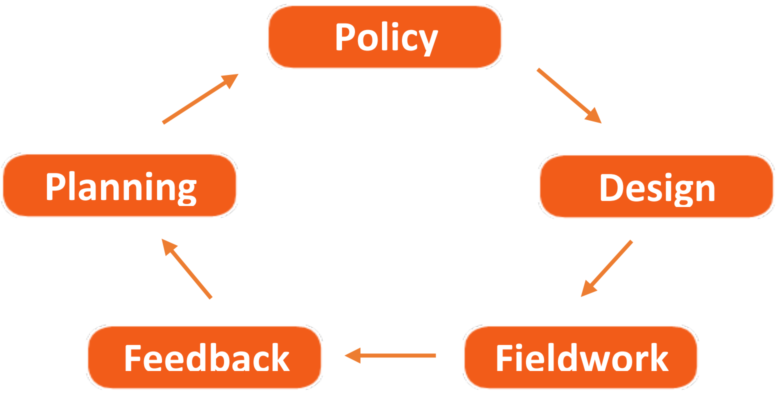


Figure 3: The Action Evaluation Research Process (Adapted from Wadsworth, 2011).

Family participation

RATIONALE FOR FAMILY PARTICIPATION

The rationale for family participation relies on five fundamental premises:

1. Substance use is a familial and social issue.
2. Families have the experience of care.
3. Families are impacted by service provision.
4. Families have a valuable contribution to make and their involvement can lead to improvements in service delivery, policy and research.
5. In many AOD services, families receive a service themselves independently of their loved ones.

Substance use is a familial and social issue

While substance use is often viewed and treated as an individual issue, or even as an individual choice, problematic substance use affects the entire social circle of the user - family members and significant others are particularly exposed to harms caused by substance use. Some conservative estimates propose that for each person with a substance use issue at least two family members are negatively affected to the extent that they need health care services in their own right (Effective Interventions Unit, 2002). Statistics from Family Drug Help's Helpline suggest that for each person with a substance use issue an average of 4 to 5 other people (i.e. partner, parents, children, siblings and close friends) are directly impacted. Substance use related harms suffered by family members include difficult or broken relationships, instability, financial struggles, violence and child abuse (UNDCP, 1995; Gruber & Floyd, 2006). Therefore, even though the main focus of the AOD service delivery is the alcohol and other drug user, the much broader ripple effect of problematic drug use cannot be ignored.

Families have the experience of care

Families familiar with managing or limiting the harms caused by substance use develop a range of coping strategies, from providing direct support and resources to the person using substances, through to distancing themselves. Something that may be useful at one part of the journey may not be helpful in other phases.

Their close and emotionally engaged care is very different from that provided by professionals who have professional boundaries, set hours of work and a framework for practice. Even when families attempt to protect themselves from care-related stress by setting limits on the time and other resources they provide to the person using substances, they generally remain emotionally affected. This experience of 24-hour support and concern forces families to develop perspectives and responses useful for the development and evaluation of treatment types and organisation.

Families are impacted by service provision

Families are directly impacted by services provided to their relatives. Family members are second only to service users in experiencing the challenges of accessing the AOD service system and the service gaps, as they often have to pick up the support roles that services are unable to provide. For example, family support is crucial while a service user is waiting to enter a service. Family members also often take care of any underage children belonging to a service user: The Australian Bureau of Statistics reported in 2005 that 31,100 children were being raised by their grandparents, mainly because of parental AOD issues (Baldock, 2007). The burden of care experienced by families deserves consideration and earns family members a place in decision-making processes.

Families have valuable contribution and their involvement can lead to improvements in service delivery, policy and research

Interaction between people who experience an issue from different perspectives will lead to each participant gaining an expanded understanding of that issue, and thus to learning about new solutions (Forester, 1996). Family members experience AOD issues closely and in a different way than AOD professionals, service users or the general public. Therefore their contribution is valuable in its own right. Inclusion of family members' perspectives in decision making processes about AOD policy, treatment and research enriches the understanding of issues at hand and can greatly contribute to overall improvement.

CURRENT PRACTICES IN THE AOD SECTOR

Family inclusive practice

Many services are providing family inclusive practice. It is not unusual for AOD services to invite family members to be involved in the individual treatment plans of a client, with his or her consent. In the interviews conducted for this manual, some service providers stated that, although they may not be formally funded for family work, they engage with families regularly. Family inclusive practice of this nature is an essential first step as this regular contact with family members makes it more likely that future family participation opportunities will be created and taken up.

Family participation

Family participation is present at a low level in a number of services, even when it is not identified as such. A lower level of consumer participation activities, such as suggestion boxes in waiting rooms or complaint systems, are also open to family members. There are also a few examples of family participation in the AOD sector at a higher level. Family members are included on a number of advisory groups which assist services in the development and evaluation of programs and initiatives. Family members are also included in various forms of participation from focus groups to committees. Involvement of family members in participation activities is still irregular, but is becoming increasingly accepted as a necessity for the AOD sector.

WHY INCLUDE FAMILY PARTICIPATION?

Substance use is a complex health issue with broad social implications. Unlike any other health issue, substance use is characterised by the belief that person with a problem is guilty of that problem. This creates a particular type of social stigma, which makes the experience of AOD service users and their families very isolating. Participation activities can have an empowering effect by placing value on these families' experiences, as well as by including them in the democratic processes and the broader community.

Family members' perspectives have a unique value in the AOD context. While the community as a whole feels the impacts of substance use in various ways, such as criminality or associated costs, most impact is felt by the families. Family members feel harms from substance use in direct and personal ways. Thus family members' experience is very relevant to the way AOD treatment and policies affect the community.

APSU asserts that family members have a right to participate in the way treatment services are run, because families are both affected by the problem and are a part of the treatment process.

Family participation as an instrument of social inclusion

Families who are impacted by AOD issues often face their problems in isolation. Creating opportunities for participation in decision-making processes has the potential of empowering not only the participating individuals, but also other family members and the broader community.

Creating participation opportunities for family members within AOD organisations has the effect of creating a more inclusive society. The absence of family participation would serve to perpetuate the exclusion of already excluded families. Social and political inclusion is in line with the values and outcomes that the AOD sector is working to sustain.

Family participation for change

Participation leads to a practical change. Allowing space for non-professional perspectives leads to understanding a community point of view on issues that are encountered and dealt with-in the professional world. This can reveal gaps in service delivery that professionals are unaware of, as well as offer solutions that professionals would not be able to develop otherwise.

Families are an unofficial, silent partner in AOD service provision. Establishing family participation can give these partners a voice, which can ultimately bring a positive change to the AOD service system for everyone’s benefit.

Family participation as an instrument of accountability

Given the impact that gaps in service provision have on families, a dialogue with family members is a duty of every service provider. It is through family participation that service providers can have truthful feedback on whether and to what degree their services are meeting the needs of the whole community.

Family participation as policy

Family participation is recognized and supported across current AOD and mental health policy frameworks.

The significant presence of service user and family participation in government policy is not always reflected in organisational policies. We do not have the complete picture of information about policies on consumer participation across Victorian service providers. However, in 2012 APSU surveyed 32 AOD organisations about their participation policies and practices. Less than half (15) of surveyed organisations had a policy or procedure supporting consumer participation at some level. This indicates that the importance given to consumer participation at the highest level does not translate on the ground level in the very organisations that work and interact with service users and their families. This is not a uniform picture, but there are clearly deficits to be addressed.

Family participation as a process

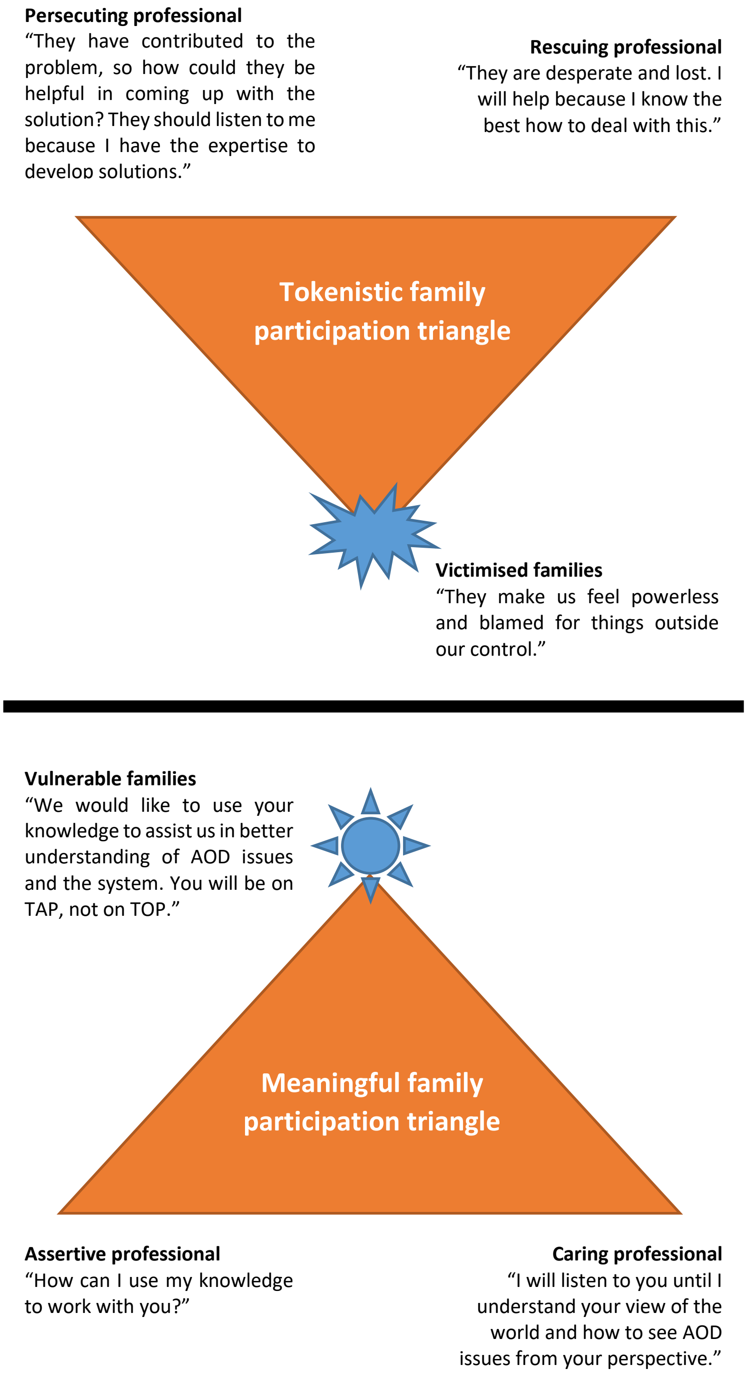
In order for consumer participation to be meaningful it needs to fit in with other existing processes in an organisation or a system. If it sits outside other processes, it cannot truly have an impact.

Some forms of consumer participation are suitable for both service users and family members, but some are not appropriate for both categories. For example, some residential facilities have consumer advisory groups (CAGs) made up of their resident clients. The focus of these groups is usually on their specific program. It would not be appropriate to include family members in a CAG of this kind because the program does not impact them in the same way that it does clients. However, many consumer participation activities are not that specific and would benefit from family members’ perspective.

Establishing family participation is a process of trial and error. Acceptance of this uncertainty will create a healthier process.

COMMON BARRIERS TO FAMILY PARTICIPATION

Family participation can benefit the AOD system and individual organisations in many ways. However, there are a number of barriers to consider.



Persecuting professional
"They have contributed to the problem, so how could they be helpful in coming up with the solution? They should listen to me because I have the expertise to develop solutions."

Rescuing professional
"They are desperate and lost. I will help because I know the best how to deal with this."

Victimised families
"They make us feel powerless and blamed for things outside our control."

Vulnerable families
"We would like to use your knowledge to assist us in better understanding of AOD issues and the system. You will be on TAP, not on TOP."

Assertive professional
"How can I use my knowledge to work with you?"

Caring professional
"I will listen to you until I understand your view of the world and how to see AOD issues from your perspective."

Illustration adapted from F. Baum's *The new public health, Oxford University Press* 2008.

Attitudes

Service Providers

In the context of family participation, professionals who maintain the role of the expert may see families as part of the problem. During our interviews with service providers, one provider pointed out that "some parents use drugs too". This is irrelevant in regards to participation.

Another view is that families are overburdened by the problems associated with their relative's substance use. Providers may approach families as helpless victims who are in desperate need of professional expertise. While these two views of families are very different, they have a disempowering effect and omit the value in the experience of a family member.

A shift in relationship is necessary whereby professionals use their knowledge to assist service users and family members, but their contribution is not to be considered superior - they are on tap, not on top. Meaningful and tokenistic family participation triangles illustrate the attitude shift and how it affects outcomes.

Family Members

Attitudes of some family members may also represent barriers to family participation. Similarly to some service providers, some family members also view AOD professionals as depositories of expertise that should not be challenged. These family members might think that "it is not their place" to have a say in decision making and they would prefer to get treatment for their relative without further involvement. Another element that prevents some families from participating is fear that their relative might suffer consequences should they voice any opinion that contradicts professionals. Stigma felt by family members also often plays a role in avoidance of participation activities.

Lack of information

Information is essential for family members of AOD service users. Lack of relevant information causes families to feel disoriented, unsupported and disconnected, and undermines the basis for family participation, and family inclusive practice. Family members need information on a range of topics, e.g. How does a service work on a day-to-day basis? What does the treatment for their relative involve? What can they expect and when? How can they support the person in treatment? The complete list of topics should be developed in collaboration with family members. Provision of relevant information will create a sense of involvement and family members will be more confident to engage in family participation activities.

Misunderstanding the need for client consent

Family participation does not require that AOD service users be in contact with their family or consider family members as significant others. Many participation activities can include a mix of family members and service users, however family participation can also occur separately, and in some instances that is the more useful approach.

Unwillingness to participate

Services often claim that it is hard to find people who are willing to participate. Some people are indeed reluctant to engage with services beyond what they feel is necessary. People whose family members are still using substances or in early treatment are often not ready for participation. For some family members, participation can raise the issues that they want to be distanced from. Organisational culture or structure that does not welcome participation may also be a reason for unwillingness to get involved. Organisations should approach and motivate family members, and make them feel welcome to provide their input. APSU has a rich database of service users and family members, and often assists organisations to recruit consumers. Advertising on the notice board in the reception area, organisational website or approaching family members who have demonstrated a desire to be engaged are also effective recruitment strategies. Communicating how consumer input has been implemented will ensure further engagement.

Stigma

Family members of people with drug dependence may have strong feelings of stigma and shame. AOD treatment and harm reduction services have been advocating for many years that drug use should be seen as a health issue, however, drug use in our society is still defined by its criminality. Consequently, some people still believe people with drug addiction have brought their troubles upon themselves and are not deserving of compassion. Family members often feel that they are guilty by association or that they are in part responsible for their relative’s behaviour. As we are talking about a feeling, it is not rational, and it reflects an intricate web of social, psychological and moral factors.

Most family members struggle to find a space where they feel safe to disclose their relative’s substance use issues and, in APSU’s experience, they often try to remain anonymous. For this reason, many will avoid participation activities. Other family members may get involved, but if there is resistance to their views, the issue of stigma is likely to arise and they will feel that their views are worthless. This can result in withdrawal from participation activities. Therefore, it is important to create a safe space for family participation and to develop a culture where staff and management welcome consumer views.

Lack of resources

Resources are a barrier for family members too. To be able to participate in a meeting or a focus group, people need to make various arrangements that may carry associated costs. It is therefore important that participation activities are accompanied by a budget for consumer payments.

Youth Participation

Young people accessing services have their own unique challenges. Navigating complaint and feedback channels may be more difficult for a young person than an adult. Furthermore, young people have different rights and vulnerabilities, which need to be taken into consideration by AOD services.

SHARC has a dedicated advisory committee made up of participants in its youth residential program, Recovery Support Services. The young people are supported and encouraged to provide meaningful and critical input into service design and delivery.

An organisation that does youth participation well is Youth Support and Advocacy Services (YSAS). It advocates for young people with the belief that young people have the right to participate in decisions that affect them (YSAS, 2013)

In 2019 YSAS appointed a former client to their board of governance. Having accessed their services from sixteen through to her twenties she has experienced first-hand YSAS service provision, from youth outreach to residential detoxes. She now sits on the board to add her voice to YSAS governance. YSAS also run a range of different youth action and advisory groups and focus groups.

The YSAS Board of Governance meets with these groups to ensure that feedback from the ground makes its way up through the organisation and is heard by those in a decision making capacity.

YSAS reimburses young people for their time and contribution. Other youth action groups include:

The Crew

A youth action and advisory group for ages 12-25 from across Victoria. The Crew meets fortnightly to help consult and advise on programs and treatment models, as well as collaborating on new ideas for how YSAS can better engage and work with young people accessing their services.

headspace Collingwood YAC

The Youth Advisory Committee (YAC) is run by a peer worker involved with youth participation. YAC meets every three weeks to help organise, collaborate and work on blogs, projects and community participation (such as speaking at schools). YAC also helps develop projects and inform policy and processes at YSAS Collingwood.

Email reception@collingwoodheadspace.org.au to find out more about the YAC or to get involved.

headspace Frankston YRG

The Youth Reference Group (YRG) also helps to inform policy and processes at the Frankston site. YRG members consist of those aged 16-24 who have used headspace/YSAS services and bring a lived experience.

If you want to know more about youth participation at YSAS, contact YSAS Youth Participation and Leadership Program Officer on: (03) 9415 8881

Read more at: https://www.ysas.org.au/youth-participation

> *"At YSAS, we uphold the right of young people to participate in decisions that affect them. We believe this participation not only empowers young people but helps to build confidence and develop new skills for all involved." (YSAS, 2013)*

Planning for diversity

In communities that may be disengaged from the service system, it is even more imperative that service providers seek input and involve diverse consumers in the decision making process. Many of the barriers to engaging people from diverse communities in participation activities will be the same as for other consumers; however, there are some obvious differences specific to these communities, such as language, cultural and physical barriers.

INDIGENOUS AUSTRALIANS

There are a number of specialised services in Victoria that are designed to cater for the specific cultural needs of Indigenous Australians. For these services, the practice of consumer participation can be readily applied in conjunction with sensitivity and respect for the cultural heritage of the people who use these services. For all other AOD services, specific processes need to be put in place before planning for consumer participation activities specific to or including Indigenous communities.

It is unreasonable to consider Indigenous people participating in services as consumers before removing the barriers that prevent them from accessing services in the first place. If the establishment of a vision statement and policies and procedures incorporate Indigenous heritage, if all staff have knowledge of the history of Aboriginal cultures in Victoria and the subsequent seclusion from dominant culture, and if systems are in place to improve the knowledge and understanding of the specific needs of these communities, then an organisation is well placed to begin collaborating with Aboriginal consumers.

Barriers can be addressed by both a cultural audit and cultural sensitivity training. A tool readily available is the Cultural Awareness and Self-Assessment Kit which can be downloaded from the ACT Council of Social Services website (ACTCOSS, 2014). The checklist evaluates policies and practices and recommends working with a specialist Indigenous AOD agency when conducting an audit. Cultural sensitivity training provides staff with knowledge and awareness of Aboriginal cultures and heritage, as well as ways of working more effectively with Indigenous service users.

The contribution of ideas and opinions by Indigenous consumers is vital in building a service model that is appropriate and respectful for all people with AOD issues. The processes outlined in this handbook require time, planning and support from both executive and staff, and specialised Aboriginal AOD services must be consulted in order to make service delivery more meaningful. This is especially relevant given the Closing the Gap campaign, a response from the Federal Government to achieve health equality for Aboriginal and Torres Strait Islander people within 25 years. One of the key commitments in this campaign is Government working to ensure full cooperation with Indigenous people and their representative bodies in all aspects of addressing their health needs (Holland, 2018).

PEOPLE FROM CULTURALLY AND LINGUISTICALLY DIVERSE (CALD) BACKGROUNDS

One of the methods used to estimate the use of AOD services by people from CALD communities is the Minimum Data Set (MDS). In NSW, the proportion of service users in 2004–05 born in a non-English speaking country was around 6% (Van der Gaag, 2007). However, the proportion of people born in a non-English speaking country in the general population was 17%. This shows a disproportionately low use of services by these communities.

The more recent CALD AOD Project: Consultation Report was a two-year initiative which came from the Victorian Government Strategy for Alcohol and other Drug Harm Reduction Plan. This project, conducted by VAADA, was to support Victorian AOD services to improve outcomes for individuals and families from CALD communities (VAADA, 2014).

In total, 50 consultations were conducted. Consultations were run as a series of semi-structured interviews covering a range of topics, while at the same time enabling respondents to raise other issues they considered important (VAADA, 2014).

Respondents from certain CALD communities felt reluctant to detail issues in regards to particular communities due to ongoing stigma and social isolation. Respondents were also hesitant to encourage stereotypes or generalisations of their own lived experience to their broader ethnic group.

VAADA's consultation data suggests their responses were based on the following concerns:

- A worker's perception of AOD use may be skewed by their immediate experience and therefore making general statements, which may or may not be applicable to the broader group, should be avoided.
- Identifying a particular community has the potential to reinforce existing negative stereotypes about that group, especially those related to illicit drug use and criminal activity.
- Making sweeping statements about any community is problematic – it can feed into the view that CALD communities are homogeneous.

> *"The involvement of CALD consumers and families [...] makes an especially valuable contribution because of its capacity to define CALD-community specific barriers of access and use of services" (Romios, McBride, & Mansourian, 2008)*

The barriers to accessing AOD treatment for CALD communities that were identified included:

- Stigma and shame associated with drug use, dissuading people in need of support from coming forward
- Lack of trust in mainstream services
- Lack of awareness of available services and how they operate
- Community perceptions that services are inflexible and insensitive to their cultural needs
- Culturally inappropriate service delivery
- Language barriers and low levels of health literacy (including knowledge of AOD harms)
- Confidentiality concerns
- Lack of collaboration between AOD and ethno-specific services resulting in poor communication flows and service breakdowns

Giving some members of a community a voice and inviting them to participate may create a hierarchy in the community where other members feel marginalised. CALD service users may also be aware that their role in consumer participation activities is limited by an unequal partnership with a service provider that has established relationships with English speaking participants.

> *"So many things are at play other than cultural norms, like availability … it is hard to be specific about any one community because with illicit drugs there is so much cross over, and emerging communities are often targeted because they are visible."- Service user*

As with Indigenous communities, organisations need to be aware of their own cultural values and attitudes and how these may affect service delivery for consumers from CALD communities. Cultural competency includes creating an organisation that is user friendly by employing bilingual staff, using interpreters and providing multilingual information. It is also essential that services are familiar with their catchment demographics and compare these with the use of their service by different CALD groups. Building long-term equal partnerships with multicultural organisations and communities is key to increasing levels of participation from CALD communities.

PEOPLE WHO IDENTIFY AS LESBIAN, GAY, BISEXUAL, TRANSGENDER, QUEER, OR INTERSEX (LGBTQI+)

LGBTQI+ inclusive practice needs to be considered as part of other culturally sensitive practices. As with other communities, it is important that service providers have knowledge of the specific needs of LGBTQI+ people.

Before considering consumer participation with these groups, organisational practice needs to incorporate several recommendations for inclusive practice that have been outlined by the Victorian Department of Health (Department of Health, 2009). These are:

- A welcoming environment
- Staff education and training
- Staff/client communication that promotes acceptance of sexual orientation, gender orientation and relationship status
- Use of documentation for seeking consent to record information and offer reasons why information is needed
- Referral and resources where consumers benefit from a database of LGBTQI+ support groups and services
- Disclosure and confidentiality where confidentiality statements are developed that are specific to LGBTQI+ and the right not to disclose is respected
- Consultation: Seek advice from representatives of the LGBTQI+ communities regarding services. Seek LGBTQI+ representatives for consumer and service advisory committees and consult and partner with LGBTQI+ stakeholders to ensure all work is led by evidence and informed by LGBTQI+ stakeholders
- Health and personal information: Ensure LGBTQI+ partners are readily recognised as next of kin
- Research: Support research projects focused on LGBTQI+ communities

Whilst adapting policies and procedures, it is helpful to collaborate with a specialist LGBTQI+ agency.

PEOPLE WITH A DISABILITY

The main barrier for people with a disability who use AOD services is access. Wheelchair access and disabled toilets are essential for engagement of this significant section of our community. People with hearing or vision impairment should also be supported and offered interpreter services and access for guide dogs. If a person with an intellectual disability (including Acquired Brian Injury, which is common in the AOD sector) is treated disrespectfully by staff, then he or she will be reluctant to seek help in the future.

When planning for participation, sensory, intellectual, neurological and physical disabilities must be considered, including those that are the result of a long-term chronic illness.

As with the other communities, planning for consumer involvement starts with organisational policy and procedure, identifying client needs and making people with a disability feel welcomed and respected. In practice this may be that disability services literature is included in any resource displays, and the education and training of staff is sourced from services within the disability sector.

Mental health and dual diagnosis

The treatment and care of people experiencing mental health issues has now become 'core business' in the AOD sector. It is estimated that 75% per cent of people with a substance use problem may also have a mental illness (Better Health Channel website).

With the advent of the Victorian Dual Diagnosis Initiative and the federal Improved Services Initiative, many AOD services are dual diagnosis capable.

It is important when seeking input from AOD service users to remember that mental health issues are going to be as relevant as AOD issues. Mental health must be on the agenda when discussing the design of a survey or the content of a focus group. Service users need to feel comfortable talking about their mental health issues and must believe that an organisation wants to hear their views. It is essential that services create a culture where anxiety, depression, bipolar disorder and other psychiatric illnesses can be freely talked about, not only as part of treatment but also as part of consumer participation.

The same principles used in consumer participation for people with substance use apply to people experiencing a dual diagnosis (see *Principles and practices*). However, many people with a diagnosed mental illness may not wish to identify as having a 'drug problem' or may not view their drug use as problematic. Conversely, people with a diagnosed substance use disorder may not be willing to acknowledge their mental health concerns. Moreover, as the AOD sector has in the past referred those with mental health issues to mental health agencies, AOD service users have been 'trained' or led to believe it is better to keep mental health issues to themselves.

When planning consumer participation activities that relate directly to dual diagnosis, there may be a lack of service users willing to identify as having a dual diagnosis. Creating a culture where mental health can be openly talked about in the AOD sector will help improve this.

Occasionally a service may wish to seek input from mental health consumers whether or not they have a co-occurring drug problem. If this cannot be done through the agency's own service users or APSU's database, the Victorian Mental Illness Awareness Council (VMIAC) can assist.

The Eastern Dual Diagnosis Service is also active in supporting AOD and mental health services to incorporate consumers and carers in the implementation and delivery of service and system change.

PART TWO:

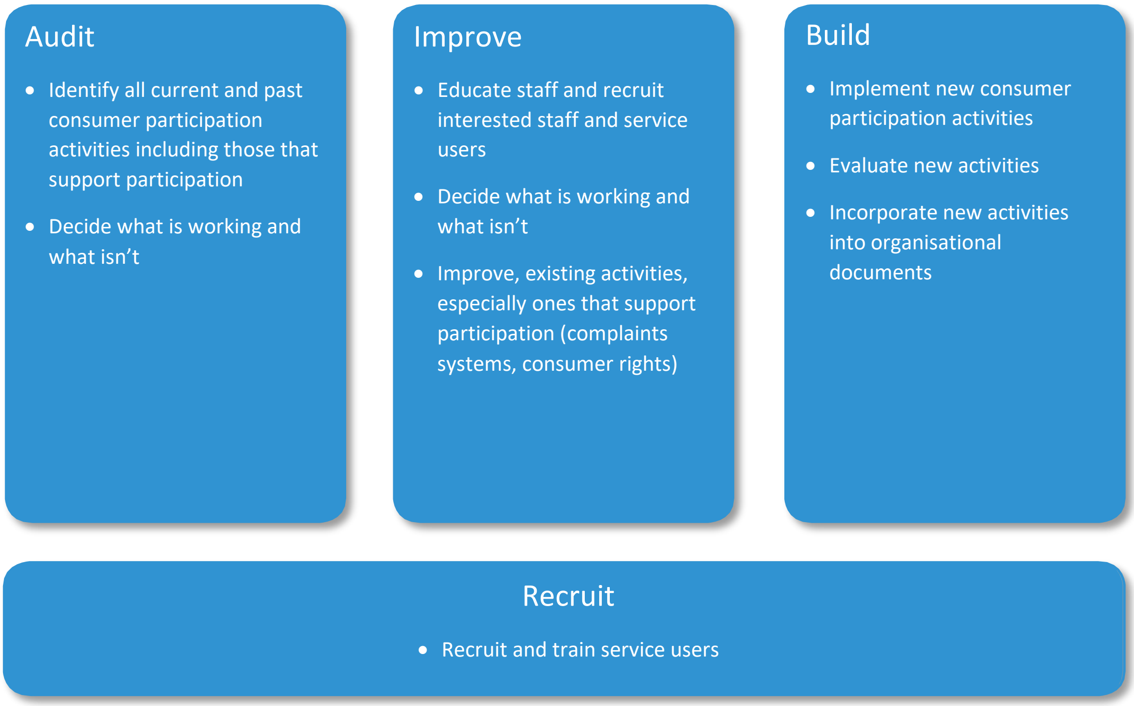
A plan for organisations

FAMILY PARTICIPATION

Moving forward

Involving consumers in organisations can be a difficult task. It is hard to know where to begin, how to go about the recruitment process and which tools to use. The idea is not to try to achieve comprehensive participation overnight. It is a process that requires time and relationship building. The aim is to gradually and sustainably increase the level at which service users can participate.

It is strongly recommended that organisations assess the consumer participation activities they already have, and spend time improving these before going on to build new opportunities.



Audit

- Identify all current and past consumer participation activities including those that support participation
- Decide what is working and what isn't

Improve

- Educate staff and recruit interested staff and service users
- Decide what is working and what isn't
- Improve, existing activities, especially ones that support participation (complaints systems, consumer rights)

Build

- Implement new consumer participation activities
- Evaluate new activities
- Incorporate new activities into organisational documents

Recruit

- Recruit and train service users

Figure 4: A plan for organisations

"We want a plan, it feels like we are building the aeroplane whilst we are flying."
– Service provider

AUDIT CURRENT CONSUMER PARTICIPATION

It is important for an organisation to assess what it is already doing. Most AOD services have a complaints policy and most provide information to clients, often in the form of pamphlets in waiting rooms. Many organisations have also attempted consumer participation projects at a higher level at one time or another. When auditing consumer participation activities within an organisation, consider the following questions.

Current activities

Complaints system

- Is anyone making use of the complaints system/grievance policy?
- How are service users informed of the complaints policy?
- If clients are not using the system, why might this be?
- Is the complaints system too complex?
- Are clients encouraged to voice their complaints (as well as their compliments)?
- What is the staff culture around complaints?
- What happens after a complaint is made?

Complaints systems are one of the foundations of consumer participation; they are the most basic of feedback mechanisms but are next to useless if consumers are unaware of them or are not encouraged to use them. An organisation could ask clients what they think of the complaints system and how it could be improved. This could be done as a survey, a focus group or an informal group at a residential service. This in itself raises the level of participation from information level to consultation level.

Information provision

- Are clients fully aware of the services you provide?
- Are the pamphlets of other services on display?
- Is information easy to see and is it in service user-friendly language?
- Is your display area too ‘busy’?
- Has your service provided all information relevant to your service users, not just the services/treatment options your service wants to promote?
- Have you considered that you may be limiting a service user’s power to be involved in their own treatment by only providing certain information?

Consider ways that your organisation could find out from service users what information they would like to receive. This would again bring the consumer participation activity from information provision to the consultation level. You could also involve service users in the development of new information resources (partnership).

Suggestion box

- Has your organisation got a suggestion box?
- Is it checked regularly and by whom?
- Where do the suggestions go? Is there a policy for the suggestion box? Is the process transparent and is it followed?
- Are any changes made to the organisation as a result of the suggestion box?
- If changes are made as a result of suggestions, are clients informed about the change?

There is not much point in having a suggestion box if it is never emptied or if suggestions reside in a filing cabinet. That is tokenistic.

Surveys

- Has/does your organisation conduct surveys, including exit surveys?
- Who designs the surveys?
- Are service users ever involved in designing surveys?
- What happens to the information collected?
- What is the information used for? Is there a policy for this? Is it followed?
- Consider why surveys are conducted. What purpose do they serve?
- Does the survey process improve services for clients?

Some surveys may be done as a matter of course, perhaps as part of an evaluation process for various programs. If the information provided is not acted upon in some fashion, there is little point. If it is always staff who design and implement surveys, valuable information may be missed.

Past activities

Sometimes activities have been attempted or completed in the past but are no longer being conducted. Past consumer participation activities might not be obvious and staff members who were involved may have left the organisation. Search computer files and ask current and former staff. Long term clients may also provide some clues. Look for information that answers the following questions:

- What consumer participation activities have been undertaken in the past?
- What worked?
- What didn’t and why?
- Why did the activity end?
- What barriers were encountered?
- Was there any damage done to the trust relationship? With staff? With clients?
- What needs to be done to address any damage caused by the activity?
- What can be learned from this experience? What can be used in the future?

There may be many reasons why consumer activities have been attempted in the past but have since disappeared. Staff may have found it difficult to recruit service users. Recruited service users may have found it difficult to actively participate because of lack of appropriate training. Consumers may have become disillusioned when their input did not seem valued or perhaps the purpose of the activity was not made clear. The activity may have been successful but ceased when the organisational structure or management changed, certain key staff left or the funding or project came to an end. It is important to assess the reasons why the activity may not have been successful and to address any damage done to the trust relationship that occurred at the time (for both clients and staff).

Organisational readiness

Involving consumers can challenge the existing dynamics within organisations. In order to avoid this becoming a negative experience, organisations need to build their capacity for this process. Capacity building for consumer participation should involve all staff in training, discussions about power relations and brainstorming how consumers could fit in the governance structure.

Identifying the organisational culture around consumer participation can prevent unnecessary barriers to participation later on. It is important to address the following questions;

- Does the organisation have a consumer participation policy?
- Is the board supportive of consumer activities?
- What are staff attitudes towards consumer involvement?
- What current/past experiences, both positive and negative, have influenced these attitudes?
- What resources are available for consumer participation?
- What supports are available for service users involved in participation?
- What are the known barriers to participation that apply to the organisation?
- What level(s) of participation does the organisation currently offer?
- What level of participation is the organisation comfortable at aiming towards?

The ‘Consumer participation audit tool: User guide & tools’ (NADA 2019) has been developed by NADA to assist support organisations to gauge where they are currently situated in relation to consumer participation in service delivery, policy and program development, access and equity, and capacity building.

IMPROVE EXISTING CONSUMER PARTICIPATION PRACTICES

Once an organisation has established what it is already doing and how well it is going, it is time to reflect on how this can be improved. After having done an audit and deciding what works well and what doesn't, start to plan what action to take to improve existing practices.

Look at the examples in Part Three of complaints systems, information provision, suggestion boxes, surveys and service user groups for ideas.

Get others involved

It may be practical to form a small committee to address consumer participation within the organisation. Use enthusiastic staff members who already support the notion of client involvement, or a colleague from another sector who already has some experience in consumer participation. It might be useful to include one or two staff members who are skeptical or resistant, as this may help with ownership of future projects.

It is important to educate staff and board members on the value of consumer participation. It does not necessarily have to be formal training sessions; consumer participation could be a regular agenda item at staff and board meetings.

Involve service users early

One of the drawbacks of not involving consumers at the start of the planning process, or only when plans are at the implementation stage, is that they are deprived of the opportunity to influence the direction of the planning. The organisation may have one or two service users who have expressed the desire and have the capacity to be part of a consumer participation committee. If this is not the case, then the committee could consult small groups of service users on particular topics, such as how to improve an existing practice. Training can then be developed around participation at higher levels.

It is recommended that at some stage clients should be encouraged to put their names forward as being interested in consumer participation activities at an organisation.

Make service users aware

It is essential to make clients aware of existing and new participation opportunities, and encourage them to become involved. AIVL consumer participation research demonstrates that service users are often unaware of the participation opportunities available to them. For example, only half of service users knew that their service had a complaints system (Bryant, Saxton, Madden, Bath, & Robinson, 2008a, p. 135). The scope and limitations of the activities should also be made clear to service users.

Write a consumer participation policy

A consumer participation policy is a statement of intent and commitment. It doesn't matter what level of participation the organisation is currently at or what level it is aiming to get to, a policy paves the way for procedures to be developed, and detailed plans can follow. Consumer participation policies should contain broad statements and be adapted accordingly as new plans and projects are undertaken.

The policy should be written in plain language in order to be accessible to clients and should be publicised to both staff and clients. See *Appendix 1* for an example of a consumer participation policy.

Develop or adopt a charter of rights and responsibilities

Organisations should develop their own charter of service users' rights and responsibilities, or adopt the existing Victorian charter (See Appendix 2). The Victorian charter, however, may not cover all the areas that are necessary for a specific organisation, so it is advisable to develop a specific organisational charter that covers those gaps. Family members' rights and responsibilities can be included within the service users' charter.

BUILD NEW OPPORTUNITIES FOR CONSUMER PARTICIPATION

Start small

The best way to make plans for consumer participation is to gradually move up to increased levels of involvement. A firm foundation at the ‘information’ level may then lead to ‘consultation’ activities. Start small, especially if there is a need to demonstrate the viability of consumer participation to staff. Gain experience with small projects before launching into large, high level projects.

On occasion there may be a chance to ‘jump ahead a couple of levels’. For example when a new project is started and consumers could be involved in the planning (partnership level). Take whatever opportunities arise to involve service users, but be careful not to involve service users without providing adequate training and support or promise more than can be delivered.

Involve service users early

Consider how a new participation activity will help improve the organisation and its services. Avoid tokenism by ensuring that there is real opportunity for things to change as a result of service user input, otherwise there is no real point in asking for it.

Involve consumers as early in the process as possible. For example, if planning a survey, get service users to help design the survey or ‘road test’ it before its general application. Once the survey is conducted, plan how the feedback will be used. If a service user group is set up, decide how their input can be fed into decision making mechanisms. For any consumer participation activity, provide feedback to clients on how their input was used and why it was valuable.

Sustainability

Although there is a place for one-off consumer participation projects, it is preferable that any new project is sustainable. Project outcomes can be lost if staff and client turnover is high. Once an activity has been implemented and evaluated, consider writing it into the consumer participation policy as an ongoing practice. For example, if a general client satisfaction survey is conducted, plan to do it at regular intervals. If a service user has become part of a planning committee for a new program, make it a policy to have consumer involvement in every new program initiative. This helps to keep up the momentum of involving clients in projects and avoids disillusionment with the stop -start nature of one-off projects.

RECRUIT SERVICE USERS

Having consumers who are willing and able to participate in consumer participation activities, especially activities of a higher level, can be a difficult task. Sometimes there are numerous potential participants but they can't be contacted. Other times participants are available but there are no activities in which to engage. Recruitment of consumers, therefore, needs to be a systematic and ongoing process.

It is best for organisations to develop a pool of service users who are willing to participate as new opportunities arise.

Consent form

Organisations may devise a consent form for service users to register their interest in becoming involved in consumer participation activities. Written consent eliminates any privacy concerns about client files being used to obtain contact details for non-therapeutic purposes.

A consent form may contain:

- An explanation of consumer participation in plain language and as it relates to the organisation
- Contact details
- Length of time of consent
- The type of activities a service user might be interested in.

Organisations should develop a procedure for presenting consent forms to their clients. This, of course, should not be done during the client's first contact with the service but when they have had a chance to settle in. For example, a counsellor may be required to present and explain a consent form during a client's third or fourth visit.

APSU membership

Consumers often use more than one service or move from service to service, and there are a variety of ways that they can contribute to the AOD sector besides being involved at an individual agency. APSU provides training and information to interested consumers and is regularly requested to provide trained consumers to organisations and government for consumer participation activities. It is therefore recommended that, in addition to an agency based consent form, organisations encourage their clients to sign up for APSU membership. In this way, service users can take advantage of training and other opportunities offered by APSU, and agencies can take advantage of a APSU's statewide database of service users who are willing to participate in consumer activities.

Training and support

Training is an essential component of higher level participation. There is no 'one model fits all' package for consumer training, as each consumer participation opportunity is unique and each consumer already has his or her own skills and abilities. However, APSU offers a series of training workshops that teach the basic skills and knowledge required for higher level participation, and sessions can be modified to suit certain groups and situations.

Organisations should also train consumers when the need arises. As service users are recruited for particular activities, the organisation should provide relevant information and training required for that specific activity. It is recommended that organisations do not train service users unless there is a specific opportunity in which they can become involved. Being trained for a job that doesn't exist is disappointing to say the least.

Adequate support needs to be provided for consumer participants, similar to that of staff supervision, with available resources permitting. APSU can be called upon to provide supervisory support to consumers engaged in participation activities. External independent support for consumers, especially from people who understand what it is like to participate in a consumer role, is valuable.

LAYING THE GROUND FOR FAMILY PARTICIPATION

The process of family participation can be developed alongside service user participation as part of broader consumer participation within the organisation, or it can be added to existing processes for consumer participation.

With some investment in planning, training and collaboration, an organisation can adjust some of its procedures to acknowledge the value of family members' experience, e.g. including family members in a client's treatment plan and ensuring that there is a pathway for both peer and professional support options for families.

Include family members in the individual treatment plan

Service users should be offered the opportunity to have a family member, friend or a significant other involved in their treatment. Service providers should evaluate which step of the process is the best time to ask this question. It can be addressed during assessment or, if the service user is not ready at that time, the question should be raised throughout the treatment journey. Clients have the ultimate say regarding involvement of their family, when it will happen and to what degree. Family involvement cannot override clients' privacy and their overall ownership of their recovery. However, clients can be made aware of this option and the benefits that family involvement can bring.

Even a minor family involvement can be very beneficial. For example, giving family members regular updates on treatment progress can help client recovery.

Provide peer support groups for families

Peer support groups are successful in overcoming stigma and isolation. For families, peer support groups are a safe non-judgmental space where they can meet with other people facing similar issues, learn self-care strategies and discover their own hidden resources in dealing with substance use issues.

Setting up a peer support group for families requires a small investment from the organisation: a space for meeting and a worker to act as a liaison to induct peers in relevant organisational policies. SHARC can provide assistance with the group set-up and train the peer facilitators.

Accommodating a family peer support group signals that the service provider acknowledges the experiences of family members. This creates an environment where family members are more eager to engage with the organisation and, consequently, allows access to family members who may be interested in participation activities.

There is a common misconception that peer support is a form of consumer participation. The two concepts, however, have a very different focus. Consumer participation aims to include people impacted by an issue in decision-making around that issue, therefore the character of consumer participation is political. Peer support aims to provide support from people who struggle with a similar issue, so the character of peer support is therapeutic.

Offer professional support for families

Creating a working relationship with specialised services that work with families will assist with providing effective referrals for family members who would benefit from professional support. This allows a service provider to have a conversation with a family member about how they are coping with the situation and offer relevant support. These linkages help build a relationship of trust and understanding with the family members.

Connect with organisations that work with families of people who use drugs and alcohol, such as Family Drug Help (FDH), a program of SHARC. FDH can suggest options for support of family members, including a statewide network of support groups.

INFORMATION

Information is a particularly important element of consumer participation for families, as their experience of services is less direct than it is for service users. Clear and relevant information will give families a better understanding of their relative's journey and allow them to be more involved and to feel better connected with services. It is good practice for service providers to consult family members about the information they consider relevant, rather than assuming what they need to know.

Develop an information package for clients' families

Every client should be asked who they want involved in their journey and an information package should be given to those they indicate. The package should contain information about what the service user will be doing, the day-to-day operations of the service, how a family can support the service user and the relevant policies of the organisation and support available to family members.

You could:

- Convene a small focus group of 5-10 family members to develop a list of relevant information, both generic and specific, for families of people in treatment in your organisation.
- Reconvene the group for the evaluation of information material once it has been developed. If information packages already exist, evaluation of these can be your first step.
- Involve your clients in the development of information for families. Service users know how a program works, so they are likely to have a better idea of what their families should be informed about.

Provide generic information for family members

In addition to information developed for clients' families, there should be information for family members of people who are not currently engaged in a service. This should include information about the organisation, and where other information about substance use issues is available, i.e. websites and helplines, such as DirectLine (1800 888 236) and Family Drug Help (1300 660 068).

Hold information sessions and events

Information sessions offer more direct engagement and the opportunity to network with family members. Depending on the services offered by the organisation, information sessions can be delivered on a range of topics, from program activities to the effects of various substances and coping strategies.

Adopt family inclusive practice

Family inclusive practice (FIP) goes hand- in- hand with family participation. Organisations should develop a FIP policy, depending on how it fits within their organisational mission and values. This policy is an opportunity to demonstrate recognition of the value that family has for the overall wellbeing of the individual, and therefore the important role of family in the process of recovery.

Include family in policy

The value of family experience should be acknowledged in an organisation's consumer participation policy. Involve service users and family members in conversations about policy. An example of a consumer participation policy that encompasses family participation is available in Appendix 1.

Inform families of the organisation's complaints procedure

Family members, like service users, should be informed about and have access to the organisation's complaints procedure.

FAMILY PARTICIPATION ACTIVITIES

Having in place information, policy and the strategies to engage family members will allow the development of family participation activities at consultation and partnership levels. Not all forms of consumer participation are appropriate for family members. It is important to remember that service users need to be involved in tailoring the programs, services and policies that touch them directly. This does not mean that family participation is less important, but the space for involvement of family members may be limited in some circumstances. It is therefore important to carefully assess if families can fit in the already existing participation activities or if new opportunities for participation should be created.

We suggest a few family participation activities below. These include suggestion boxes, surveys, focus groups and advisory groups.

Family representatives on committees

Consumer representation on committees is growing in the AOD sector. While there are some examples of consumers on committees, inclusion of family members is still not common. Representation on committees is high level participation and a form of partnership between consumers and professionals.

Committees are generally composed of professionals who have experience and knowledge that will enrich the project at hand. Family members have the same role, but their knowledge is derived from their lived experience. Our society values professional or academic experience much more than lived experience. Participation in a committee with professionals can therefore be intimidating for a family member. Some professionals may challenge what a family member can offer, and family members themselves can be overwhelmed by a sense of inferiority. However, with the correct structure in place, the presence of a family member can significantly enhance the expertise of a committee, and thus the outcome of the project.

By including a service user or a family member on a committee, it is important to clarify from the beginning that all committee members are equal and to reinforce that attitude throughout the process, i.e. terms of reference. The chair, as well as the other members, needs to make family members' opinions welcome. If a family member is not offering an opinion, it may mean that he or she is not feeling comfortable, so they should be explicitly invited to express their views.

Participation on a committee requires well-trained family members. It is a representative role, so people who fill it need to have an understanding of a variety of views from the community they represent. Training helps family members in developing representational skills, but some level of bias cannot be entirely avoided. Bias should not be considered a problem specific to family participation, as it is equally valid for professional members on a committee.

Family members in representative roles need the opportunity to debrief regarding their experience. APSU has the experience in providing this form of support and welcomes any requests for it. Family members who participate on a committee also need to be financially reimbursed for their time.

Depending on the project a committee is working on, a consumer representative can be a service user, a family member or both. Most committees would benefit from both service user and family representation, but some committees may need only one of the two.

Family representatives on committees – advantages:

- Family views are represented at a high level
- Permanent access to a highly trained family member
- Consumer participation is embedded faster in the organisational culture
- The cost for one or two representatives is rather low in relation to the significant benefit that they bring.

Family representatives on committees – disadvantages:

- This form of participation is insufficient in itself and needs to be combined with other forms of participation at a lower level.
- Success depends largely on the attitudes of committee members with professional background. If their attitude is negative, family members will get discouraged.

Recruitment

Strategies described in the “Engaging families” section will help in accessing family members who are willing to be involved in participation activities. However, family members of clients who are currently in treatment are often reluctant to get involved in participation beyond the client’s treatment plan. In APSU’s experience, most family members who choose to participate have had some time distance since their relative’s treatment.

Recruitment for family participation can be advertised on a notice board, or family members who have demonstrated an interest in becoming actively involved can be approached directly. APSU can also be used as a recruitment resource. APSU regularly assists various organisations and government bodies to recruit consumers from its membership and provide training that prepares both service users and family members for involvement in participation activities.

Tips on family engagement:

- Give attention to each stage of a participation activity: preparation, recruitment, training, execution, analysis, feedback, implementation and evaluation.
- Find champions amongst participating service users and family members.
- Involve consumers from the beginning. Your champions will be helpful in preparation.
- Practice a variety of forms of participation. This will enhance cultural change and the learning outcomes.
- Train new service users and family members at least once a year. People move on, so it helps to have new consumers ready to participate.
- Involve the entire organisation in the training process. Ask various managers and staff members to talk to consumers about their role.
- Doing a few surveys and focus groups can be a good learning process before starting an advisory group.
- Surveys and focus groups will be more successful if prepared or reviewed by someone with experience in social research.
- Do not try to control the process.
- Consumers are working *with* you, not *for* you.

PART THREE:

Practical examples of consumer participation

Practical Strategies

While theory is necessary to form the basis for good practice, it is always the practice itself that brings a subject to light. This section presents a broad range of examples and case studies to demonstrate the use of practical strategies. These include examples of projects and activities that APSU has been involved in, along with examples from other Victorian, national and international organisations.

Part Three is arranged in four sections:

A. Organisational examples
B. Education and training examples
C. Policy development examples
D. Research examples

These correspond to the Domains of Participation (as discussed in *Part One*).

Each section discusses the reasoning behind a particular consumer participation activity, its uses and one or two practical examples. The participation activities in each section are arranged from low level to high level participation (see Levels of Participation in *Part One*).

The examples presented come primarily from work undertaken by APSU, in partnership with other organisations and service providers. Some older examples have been retained from the first edition of this handbook as, though dated, they profile useful examples of how consumer participation has been undertaken in diverse and challenging settings.

The *Appendices* section contains further resources relating to the practical strategies.

A. Consumer involvement in organisations

INFORMATION LEVEL

Giving out information is not participation, as the information flow is one-way. Providing information does not change how services, policy, research, treatment or care are conducted. However, information is often used to support or invite participation. For example, information about how to access a service and what is involved in the care or treatment of a health issue provides necessary information required for an individual to make decisions about their own treatment. Without this information the service user would be less able to make an informed decision about their health care. For this reason, information is usually identified as supporting participation.

Information provision

Written information is often displayed in waiting areas of AOD services. This may include pamphlets on AOD or related services, harm reduction and other health care information. Some services also have notice boards communicating forthcoming events, new programs/services and consumer participation opportunities. Information provision can also be achieved via direct care. Counsellors, GPs, case managers and support workers regularly supply service users with verbal information about their condition and treatment options.

It has been said that ‘knowledge is power’. It is important that organisations do not censor any information that is provided. When providing information about a broad range of treatment options, organisations should not limit or remove service users’ power by making decisions about which information is best for them. This right to receive adequate information on all services and treatments is part of the Victorian AOD Charter (See Appendix 2 *Victorian AOD Charter*).

Service providers should consider ways to find out from service users about the sort of information they would like to receive. This can raise an information provision activity to consultation level. Organisations could also involve service users in the development of new information resources such as pamphlets or brochures (partnership).

Services directory for drug and alcohol users

Fitzroy Legal Service has produced a comprehensive handbook for AOD consumers that includes; a full listing of all treatments, self help groups, agencies and other helpful information for people affected by AOD use in Victoria.

Fitzroy Legal Service Services Directory for Drug and Alcohol Users 2018 edition, Fitzroy Legal Services Inc, 2000. The hard copy of the book is currently unavailable but the contents can be downloaded online at: https://www.fitzroy-legal.org.au/vicdrugguide

Information for SHARC Consumers Brochure

This brochure was developed and co-designed with input from the whole SHARC community including program participants, service users, family members, volunteers and staff. The process was driven by the SHARC Consumer and Carers Advisory Committee, with a process of drafts and feedback leading to the finished product.

See Appendix 3

Consumer rights

Victorian AOD Charter

AOD service users, like all citizens, have significant privacy rights as well as those provided for under the Equal Opportunity Act and the Victorian Charter of Human Rights and Responsibilities. More specifically, the Victorian Alcohol and other Drug Client Charter sets out the specific rights and responsibilities of AOD clients and agencies. APSU was closely involved in developing this charter.

See Appendix 2.

Complaints process

Complaints systems are one of the foundations of consumer participation as they are the most basic of feedback mechanisms. An effective complaints process provides the opportunity for consumers to participate at a consultation level.

Service users should be educated about the complaints system, encouraged and, where required, assisted to use it. As most organisations have a complaints policy, it may be the first opportunity for service users to provide feedback. An effectively utilised complaints system can identify a service's weak spots and can be a used as a quality assurance tool. Staff need to be educated about the benefits of service users having their complaints heard. A solution-focussed complaints system and culture will ultimately improve morale and open up opportunities for training and support, benefitting both staff and service users.

Verbal complaints treated seriously at a housing service

(HomeGround Servicesd, 2008).

A housing agency based in Melbourne observed that the threshold for their complaints system was too high. People were only motivated to make complaints when the issue was very serious. In addition, the process itself was too complex and time consuming. Service users were more likely to complain informally.

The organisation decided to develop a new policy whereby staff were required to document verbal complaints. A response was then given by the organisation and the complaint was followed up. As the nature of each complaint was recorded, themes could be easily identified. These were treated like 'near misses' in an occupational health and safety log, and the organisation could respond in a proactive way to common grievances. The more formal complaints system has been retained for serious grievances and the organisation has adapted its practices to accommodate service users' preferred means of communication.

See Appendix 4: SHARC Feedback Brochure

CONSULTATION LEVEL

Consultation is used to find out what consumers think of something. Consumers may be asked about existing services or facilities, new proposals or how to identify areas for improvement; however, the service remains in control. Consultation can improve services and increase acceptance and consumer confidence in the organisation.

Consultation is only considered to be participation when the information gathered is used to make or change policy, or for planning, research or treatment. Too often, consumers are consulted but nothing is changed as a result. If an organisation is not willing to consider making changes as a result of the consultation process, it is better not to ask for feedback.

Confidentiality

It is important to provide opportunities for service users to contribute their feedback anonymously. Many service users fear that by making negative comments or criticism they will alter or jeopardise their treatment. Others may feel that to criticise is to be disloyal. Written, anonymous feedback ensures maximum privacy. Face to face feedback can also be relatively anonymous if non-clinical staff or external staff are used to gather feedback and report on it. In this way, a service user's identity can be kept reasonably confidential within the organisation.

Suggestion boxes

This form of feedback mechanism should be available for all service users and family members. Suggestion boxes can be placed in different areas of an organisation, but there should always be one in the reception area. All consumers should be explicitly invited to leave suggestions or comments about their experience of the service.

Regular checking of the suggestion box and regular feedback about implementation (i.e. monthly or quarterly) are essential for this form of participation to be meaningful. Feedback about implementation of suggestions and comments should be made available; for example, it can be placed on a notice board in the reception area and/or communicated in newsletters. The same principles apply to implementing online feedback systems.

Suggestion box advantages:

- Cost-free
- Affirms that the organisation is interested in the views of the community it serves
- Allows anonymous feedback
- Permanently available.

Suggestion box disadvantages:

- Does not provide a deeper understanding of feedback
- Insufficient as a stand-alone form of participation
- Not very engaging
- Consumers, particularly family members, rarely use suggestion boxes
- Bias: suggestion boxes gather only the views of those people inclined to give suggestions

Macarthur Drug and Alcohol Service suggestion box

(NSW Health, 2015)

Macarthur Drug and Alcohol Service (MDAS) in NSW developed a system for its suggestion boxes. A box is on display at each of its clinic sites and is emptied on a weekly basis. All suggestions are reviewed at the weekly staff meeting as an agenda item. The staff discuss suggestions and agree on a decision about a response. This response is then conveyed to service users via a notice board. The staff also find it helpful to explain to service users about why some things cannot be changed. For example, service users complained about the time spent in the waiting room before pharmacotherapy dosing; and MDAS was able to respond by explaining the reasons for this, which increased clients' understanding and acceptance of the waiting room experience.

A review of foundational practices

Information provision and basic feedback mechanisms are present to some extent in all agencies and form the foundation for consumer participation in AOD services. It is important to get these strategies working well before moving on to higher levels of participation. The following example demonstrates one agency's review of these practices and the development of an integrated approach to providing information on rights and giving service users an opportunity to provide meaningful feedback.

Uniting Regen's Client Charter and feedback mechanisms

(ReGen, 2017)

In 2007 Uniting Regen identified the need to improve its consumer feedback processes. The following timeline gives a broad overview of ReGen's journey of consumer participation from 2007 – 2016.

Pre 2007: ReGen used a complaints system, client satisfaction surveys and a suggestion box to gather consumer feedback. Several small-scale projects were undertaken to increase consumer participation. While these were positive experiences for consumers and staff, they had little lasting impact on operations. There were no budgeted funds, staffing or leadership groups allocated to consumer participation.

2007: A Quality Innovation Performance (QIP) review highlighted the importance of a comprehensive, consistent and integrated process for client participation. ReGen staff set up the Client Feedback Working Group (CFWG) to review and increase client involvement. CFWG reviewed existing feedback documents, benchmarking against the Victorian Charter of Human Rights and Responsibilities and consulting with clients and staff. CFWG decided that a Client Charter would best describe the partnership ideals with clients.

2008: A two-month trial was conducted of the new processes. Data was gathered and changes were made before implementing the final version across the agency.

2007 – 2013: APSU consulted with ReGen on an informal basis, advising on consumer participation, the setting up of new projects and attending staff meetings.

2011: An audit was conducted of ReGen's practices in regard to client participation, cultural diversity and family inclusiveness. This was in response to a QIP report from ReGen's 2010 reaccreditation, which identified a number of recommendations.

2012: In response, ReGen further developed the Client Feedback Working Group, re-naming it the Service User Participation Working Group (SUPWG).

2012 – 2013: SUPWG undertook the following activities:

- Developed a consumer participation Resources folder on the staff intranet.
- Reviewed the Client Charter.
- Developed stronger informal relationships with key organisations working with or representing consumers, including APSU, Harm Reduction Victoria, NEAMI, Victorian Alcohol and Drug Association.
- Researched models of consumer participation and supportive organisational characteristics.

2013: SUPWG developed a detailed proposal for development and implementation of a Consumer Participation Facilitator role within ReGen, detailing the proposed model, goals, task and actions, reporting lines and required investment. The ReGen Board of Governance allocated funds for the new position and in May 2013, the new Consumer Participation Facilitator commenced employment at ReGen.

2014: Consumer Participation and the Consumer Participation Facilitator role was embedded into the North & West Metro AOD Service, which is a partnership between ReGen and Odyssey House Victoria, to deliver AOD treatment in the north and west catchments.

2013 – 2016: Under the leadership of the Consumer Participation Facilitator, the following initiatives were formed and developed:

- Baseline audit of Consumer Participation activities
- Consumer Participation Policy & Consumer of Code of Conduct
- Consumer Consultants Participation two-day training for consumers (three times per year)
- Consumer Consultant Meeting Group (Consumer Consultants)
- Consumer Participation Leadership Group (staff and Consumer Consultant)
- Peer support group
- ReGen Consumer Database
- Consumer presentations at ReGen group programs, staff meetings, innovation seminars and other events
- Consumer Participation in project working groups (e.g. smoking care) and new project development (e.g. Youth Catalyst Program)
- Consumer Consultant office space
- Training for consumers to participate in recruitment of staff
- Consumer feedback to Board meetings
- NW Metro AOD Services Client Satisfaction Snapshot Survey undertaken in reception areas

2016: A secondary audit compared current consumer participation activities with baseline audit. In March, a QIP review of ReGen found that Regen's consumer participation processes not only met but exceeded Standard 2.4 within Section 2 of the review: 'Confirming Consumer Rights'. An 'exceeded' rating is difficult to attain and requires leading practice to be demonstrated as well as rigorous documentation.

The accreditation report noted that:

> *"ReGen has a strong commitment to Consumer Participation, with a comprehensive range of initiatives and approaches recognising the role of consumers in service improvement, as well as their rights to quality services and to have a say." (ReGen, 2017)*

See Appendices 5-7 for Uniting Regen's Client Charter, complaints and feedback mechanisms.

Surveys

A survey is a simple way of collecting information from a large number of people. While not allowing in-depth engagement, it is an efficient way to reach a large number of consumers.

Surveys can be used to gauge service user satisfaction, provide information about specific programs or aspects of service provision and also to make suggestions for improving or changing services. Surveys are only considered ‘consultation’ if some of the information obtained is acted upon and changes are made.

Survey advantages

- Reaches a wider pool of family members
- Provides an overview of broader family views
- Relatively low cost

Survey disadvantages

- Lacks in-depth views
- May miss issues that are not addressed in questions

Before initiating a survey, services must consider why they want this information and how it will be used.

- Think about why the survey is being conducted and explain this. If a survey is only being conducted to fulfil service requirements and not to facilitate change, think carefully before proceeding.
- Write the content in user-friendly language.
- Consider providing an incentive for completing the survey (e.g. chocolate, phone cards).
- Provide assistance to people who have difficulty filling in the survey. This is best done by staff who do not directly provide services or by trained peers.
- Provide feedback to clients and staff about the information that was obtained from the survey and how it will be used.

The process should be concluded by a communication about any action arising, or lack thereof, to the survey participants. As surveys are usually anonymous, these can take the form of any open communication available to the broader community such as: the notice board, newsletter or similar.

The availability of survey platforms such as Survey Monkey has greatly assisted and simplified the implementation of surveys. APSU uses this technology on a regular basis in its ‘Your Feedback Matters series of surveys. It’s recently published a report on consumer experiences of Victorian AOD services (APSU 2019).

Windana exit surveys – St. Kilda Residential Withdrawal Unit

Based on information provided by Windana

The St Kilda Windana Withdrawal Unit asks all their clients to complete a feedback form upon discharge. Assistance is offered to anyone who expresses difficulty in filling it out. Even people who have an early or unplanned discharge are asked to participate.

The feedback forms or complaints are then directed to the manager or appropriate staff member. When required these are tabled and discussed in team meetings. The client is then contacted to discuss their feedback. The information obtained is then discussed with the team. Any issues or improvements requiring attention are then addressed with key program staff.

Interviews

Individual interviews can sometimes be helpful to gain detailed feedback from consumers. They are best used for specifically defined purposes, as they may be time consuming and, therefore, only able to provide information from a limited number of people. The benefit of individual interviews is that they can be used where literacy is an issue, and they can help build rapport with service users by exploring themes in detail. In addition, information not directly asked for in a survey may be forthcoming in an interview.

Interviews are best conducted either by staff not normally involved in direct service delivery, or by outside workers or trained peers.

Involving family members in the evaluation of residential rehabilitation services

(Brooke & Berends)

Turning Point Alcohol and Drug Centre, on behalf of the Victorian Department of Human Services (DHS), conducted an evaluation of four Melbourne rehabilitation services to determine the extent to which they met their service and funding agreements. As well as service providers and service users, significant others were included in the evaluation process.

The following factors provided a rationale for including significant others in the evaluation process:

- Involving family members in the treatment of problematic substance use is more effective than treatment based solely on the individual.
- Family members have needs that should be considered separately from those of the drug dependent person.
- Despite conflict within families, the dependent person is often still in contact with family members.

A total of 51 clients/ex-clients took part in focus groups for the evaluation, and they were asked to provide contact details of family members who might also be willing to take part. The clients were asked to make contact with their family member and inform them of the project.

A total of 18 family contacts were provided. Most respondents were mothers or siblings of service users, although two were the carers of a service user’s children. Telephone interviews took place after an explanation was given and consent sought. The interviews were semi-structured and involved questions regarding involvement with the service, impressions of the service and any suggestions for improvement.

Participants were informed of the availability of the final report of the evaluation project. Results indicated that some family members wanted more information about the rehabilitation service and wanted to be more involved in their loved one’s treatment. Others were happy with the information provided and their level of involvement. Family members also indicated a desire for information and support for themselves.

Focus groups

Focus groups can be a great way to ask consumers what they think about a particular issue and, if well managed, can offer a chance for consumers to voice their opinions and be heard. They have the advantage of allowing the participants to discuss the topic openly and in more depth, which results in gathering more meaningful data than with a survey. However, these two forms of consultation can be combined, with an initial survey helping in the preparation of a focus group. For example, a survey can indicate which questions need a more thorough consideration through a focus group.

Focus group advantages:

- Provides in-depth understanding of participants' views
- Allows focus on a specific topic.

Focus group disadvantages:

- May need a considerable time investment in preparation and analysis
- Requires a budget for consumer payments.

Focus groups are best used to gain detailed qualitative information on a specific issue from a small group of people, although a series of groups will ensure a range of consumers has been consulted. Groups should contain no more than 15 people, although typically 8-10 is an ideal number. A series of questions designed to get people thinking is asked before narrowing down to questions to focus on a specific topic. The sessions can be recorded (with consent) and notes taken by a co-facilitator when this is possible.

Focus group participants should be informed about the purpose of consultation, as well as about the outcome. They should also be paid for their time and any expenses.

Anonymity should be protected as far as is possible. Comments made should not be directly attributable to any individual, and recordings should be destroyed or securely stored after transcription has taken place.

A trained facilitator who is not directly associated with the service should run the group. Using an 'outsider' ensures that confidentiality can be maintained and that focus group participants will feel confident about being honest and forthright in their opinions. Like any consultation activity, focus group participants should receive feedback on how their information was used.

When organising a focus group for consumers:

- Coordinate a time and place that will maximise group attendance.
- Invite more than necessary to allow for poor attendance.
- Provide remuneration or incentives for attendance, such as lunch or reimbursement for travel costs.
- Consider how many groups are needed to gain the input required.
- Consider who will be participating in the groups and whether separate groups for service users, family members, females, males, young people and adults are required.
- Develop a list of questions for the facilitator to ask.
- Allow for participants to be late and to take a short break if required.
- For more information on how to plan and conduct focus groups go to: http://www.health.gov.au/internet/publications/publishing.nsf/Content/drugtreat-pubs-front8-wk-toc~drugtreat-pubs-front8-wk-secb~drugtreat-pubs-front8-wk-secb-9~drugtreat-pubs-front8-wk-secb-9-4

Regional Roadshow Project

With philanthropy funding, APSU and the Victorian Mental Illness Awareness Council (VMIAC), the peak NGO body for people with a lived experience of mental health and emotional distress, undertook this major consultation project in 2018 (APSU, 2018).

The Regional Roadshow Project's broad aims were to connect with consumers of AOD and mental health (MH) services in rural and regional areas and to capture the experiences and issues that people who utilise services in these regions face. Working in collaboration to investigate the consumer experience of AOD and MH services was essential given the significant number of individuals who experience dual diagnosis issues.

Over a 6-month period a series of consultations was organised for five rural hubs across the state in Bendigo, Wangaratta, Wodonga, Ballarat and Traralgon. Care was given to ensuring venues were accessible and centrally located close to public transport and parking.

Flyers promoting the consultations were developed and distributed via email to MH and AOD services, and networks in each region. It was clearly communicated that consultations were exclusively targeting consumers and carers (people with a lived experience of using services) which drew some criticism from service providers, who felt excluded from what they felt was an important consultation process. After an initial lower than expected turnout, the project team learnt that the booking of venues and the promotion of these events needed to start at least 6 weeks prior to the event and be followed up with phone contacts to key personnel in each region.

The Roadshow forums were scheduled for early afternoon and ran for approximately 2.5 hrs with a break and light refreshments served. Participants registered to attend the events through social media, Eventbrite or via a phone call to organizers. Meetings attracted a diverse range of participants including consumers, carers and lived experience workers across a range of ages and backgrounds. Meetings began with introductions and an overview of the purpose of the consultation. Participants were then asked to map out the local services that they were familiar with, and were given three questions to respond to over the course of the consultation.

Questions:

1. What are the contributing factors to AOD/MH issues in this area?

2. What are the barriers to accessing services in this area?

3. What would an ideal system look like in this area?

These questions were designed to draw on people's insider knowledge to map the availability of and familiarity with services in each region and provide an avenue for discussions around contributing factors to MH and AOD issues in each area and their accessibility, quality and utility of local services. The questions were aimed at gaining insight into what changes consumers wanted to see.

At each session, APSU and VMIAC workers facilitated discussion and captured key points for the group on a whiteboard. At the end of the session APSU and VMIAC summarised key messages and discussed with participants what they would like to see come out of their consultation.

The Regional Roadshow Project provided an important opportunity to meaningfully consult with the people depending upon provision of MH and AOD services in regional and rural Victoria.

Common themes which emerged illustrate inherent problems with accessibility of services, a lack of services and inefficient service collaboration across regional and rural areas. The Roadshow highlighted a lack of consumer participation in developing and delivering improved services, and an under-utilisation of lived experience in general. However, the project outcomes also illustrated the rich, untapped reservoir of knowledge, interest and commitment among service users to be actively involved in providing better services in their communities.

See *Appendix 8 for an example of a project promotional flyer.*

Consultation process for methamphetamine family first aid program

ReGen wanted to adapt existing program material regarding methamphetamine use to reflect the experience of families or those affected by people who use this substance. Before any work commenced, ReGen organised a focus group for family members and people who have used methamphetamines.

Focus Group 1: Notes from the first focus group were used to adapt the materials and include descriptions of the experience of family members. The reaction to the focus group was significant - ReGen managers were moved by the stories, and these notes presented a new urgency for the development of the project.

Further material was developed and another focus group was organised.

Focus Group 2: Only family members attended this session. Input from this group was not only invaluable regarding the final shape of the program, but also helped realise the limitations of the group training. It was apparent that the issues that family members faced were complex and even life-threatening. Consequently ReGen wanted to do something that was useable without attempting to be everything to everyone. During this session it became evident that the order of the training material needed to be modified and that the imagery describing stages of change should be improved. In addition, the group insisted on information being added regarding safety plans and more realistic examples of strategies needed for de-escalation.

A manual was developed that included additional information and resources.

Focus Group 3: Another focus group was held once the visuals for the training material had been created. Reactions to the visuals were interesting, with participants stating that those presented were perhaps pleasing for people who used the drugs, but not pleasing for family members; family members wanted something that was hard hitting, with clear visuals of the drug and the paraphernalia.

Conclusion

After the first running of the program, a letter was sent to all of the participants of the three focus groups informing them of the commencement of the program and the positive feedback received.

In this example family members were involved after the program had been designed. The organisation maintained an open approach and accepted the modifications that were suggested by the focus groups; this openness ensured the success of the family involvement.

FDH Community forums

Family Drug Help’s (FDH) Advisory committee is made up of family members and AOD professionals. In addition to their regular role, providing advice to FDH on a variety of program-related topics, the committee members were eager to improve the understanding of AOD issues within the community. They organised community information forums, as a project of their own and relatively independent from FDH, supported by a program manager and staff.

Choice of topics for the forums was driven by experiences of family members on the committee. They chose topics that family members impacted by AOD issues felt that they needed and wanted to know about.

The first forum was a pilot project, providing information about legal issues. This forum helped the Committee’s learning process, where they chose to hold other forums on methamphetamine, more commonly known as ‘ice’.

These forums took place at two different locations and were attended by almost 300 people. Both featured a number of speakers, including people recovering from ice addiction, committee members who experienced the impact of ice through their relatives, AOD professionals and the police.

The two forums on ice were very successful in terms of number of attendees and feedback from the community. Additionally they led to establishment of a new family support group, family members seeking support from FDH, members of FDH Advisory committee receiving invitations to participate at other community initiated forums on ice and the general empowerment felt by family members on the FDH Advisory committee.

Consumer Advisory Groups/Committees

Made up of service users, including family members, from a particular service who have input into that service, Consumer Advisory Groups (CAG) or Consumer Advisor Committees (CAC) are increasingly utilised in the AOD sector but require planning and resourcing to be effective rather than tokenistic.

Advisory group advantages:

- Permanent access to trained and well-informed consumers
- Enables development of organisational culture inclusive of consumer participation
- Enables a continuous dialogue with consumers
- Allows regular discussions on various topics such as policy or service improvement

Advisory group disadvantages:

- Requires a budget for regular consumer payments
- Requires time investment in maintaining liaison with the group
- Requires time investment in embedding the group within the organisational processes.

A Consumer Advisory Group or Committee must:

- Have a clear role within the organisation and a clear avenue of providing feedback to the organisation.
- Feedback from the group must be reviewed by the organisation and taken into consideration.
- Be informed of the organisation's response to their feedback.
- Have these feedback and review mechanisms written into organisational policy and procedure.

Anything less than this may be perceived as tokenistic and lead to disillusionment of the service users involved.

> *"When [I was] on a resi council nothing was put into place. This sat on someone's desk for 8 months. We put a lot of work into it but it went nowhere. Policy needs to follow change from beginning to end. Who is responsible for each phase of change? Who backs up when someone is on maternity leave? Change needs to be put in policy so that it can exist" – Service user*

Terms of Reference are also necessary and can be written by the group in its early stages with staff support. The terms should be agreed upon and approved by the organisation and become part of organisational policy and procedure. They should address the following issues:

- What is the purpose of the group? What will it advise or comment on?
- Who can be part of the group? Does it have a quorum?
- Who performs particular roles within the group, and how is this decided?
- Who does the group report to; where in the organisation do the group's minutes go to?
- What part of the organisation is responsible for reviewing feedback from the group (e.g. clinical staff, management committee, board)?
- Who in the organisation is responsible for providing feedback to the group?
- What organisational resources can the group use (e.g. room, photocopier, computer)?
- What is the grievance process that can be used in the event of these terms not being met?
- Will group members be offered remuneration?

Organisations need to assess which is the best way for an advisory group to feed into organisational processes. It is important to prevent a consumer advisory group becoming isolated from other processes within the organisation. If that happens, the existence of the group loses its meaning and becomes tokenistic.

A CAG/CAC can be challenging to establish and maintain. Poor attendance is often a problem due to the transient nature of service user populations. Lack of skills and training of service users can make a group difficult to run. Managing the expectations of group members may also be a problem.

Group independence is often an issue. Because of the difficulty in establishing the group, a staff member may be responsible for facilitating the group, which can influence, sway or censor opinions and feedback. Where possible, a group should run itself with support from the organisation. If this is not practical, a staff facilitator can be used to establish the group and then withdraw gradually as the group feels more confident to manage itself. The use of former clients or peer workers to facilitate the group is usually the best option.

Training in formal processes can be offered to the group as a whole or to individuals with leadership qualities who are likely to stay long term. A service must be careful not to appoint a particular service user in a leadership role without the endorsement of the group overall, as this can prove problematic if the group doesn't understand why or how this person has been placed in a position of responsibility.

Due to the difficulties involved in setting up and maintaining service user groups, it is advisable to start slow. For example, the organisation may have run focus groups and can draw on that experience or on the experience of those particular participants. The organisation could set up a short term advisory group for a particular project and learn what works and what doesn't about that group before going on to establish a service user group.

Some advisory groups are not suitable for family members. Some are set up to provide input into policy and planning, or projects that need ad hoc consumer input. Depending on the topic that a group is dealing with, family members can be part of a mixed advisory group with service users or, in some instances, an advisory group composed entirely of family members can be more beneficial. In APSU's experience, mixed advisory groups are suitable for most occasions.

Consumer Advisory Committee (CAC)

SHARC and Windana Drug and Alcohol Recovery Inc. joined forces in 2015 to establish a joint Consumer Advisory Committee (CAC) to facilitate consumer participation in service provision and policy development at SHARC and Windana.

The SHARC and Windana CAC is a vital and effective forum for both organisations. The CAC is utilised to obtain consumer feedback regarding information provision, service practices and programs, service development and evaluation, as well as providing suggestions for each organisation's improvement.

At SHARC over the past four years, the CAC has contributed in meaningful ways to our service delivery.

Outcomes for SHARC, to name only a few, have included the development of:

- Our 'Information for Consumers' brochure detailing rights, responsibilities and opportunities for consumer participation.
- Our 'Feedback' brochure detailing the process for compliments and complaints and serving as a feedback submission form.
- Our online 'Feedback' portal to enhance accessibility for consumers to provide compliments and complaints.

The CAC has become a key part of our organisational structure here at SHARC and provides an untapped resource for co-design opportunities and consumer driven feedback. This has enriched our organisational culture and overall service delivery.

See *Appendix 9* for details on CAC Recruitment.

Service user advisory groups

A service user advisory group or consumer advisory group is made up of consumers who may or may not use a particular service but wish to have input into a service or into broader issues of AOD service provision, research, education or policy. A consumer advisory group is often set up for a short-term specific project such as a research project. It can also be formed to act as a long-term advisory body to a service or network of services, or to policy makers and professional educators.

Like CAGs or CACs, advisory groups need to a have clear role and terms of reference, and it can be difficult to recruit and retain members. One of the advantages of an advisory group is that it can be made up of a wider range of consumers rather than just those who use a particular service.

Advisory group for Ice education project

Turning Point, SHARC and the Bouverie Family Therapy Centre developed a collaborative project, BreakThrough, aiming to educate families on facts, coping strategies and the available support when a relative or friend uses ice. An expert advisory group guide the project development.

The advisory group membership was made up of professionals working in the AOD field and two family members impacted by a relative's ice use. The project leaders have thus included the family perspective from the beginning, and will extend this involvement to the evaluation of the educational workshops.

The professional members of the Advisory Group report that the presence of family members adds a valuable different perspective to the project. For example, it was beneficial in developing educational materials that are user friendly; family members made suggestions, which could not have been made by a professional expert. The addition of a different perspective enriched the expertise of the advisory group, elevating it from a professional to a multidimensional level.

One of the family representatives described her participation on the Advisory Group as a positive experience. Her opinions were regularly sought, which made her feel included in the group and equal with the other members. She also appreciated the learning experience that being part of this process entailed.

CONSULTATION/PARTNERSHIP LEVEL

Some practices do more to involve consumers than just consult or ask for feedback, but do not give consumers equal power in decision making.

Peer work in the AOD treatment sector

Another form of consumer participation in the AOD treatment sector is for people with lived experience of alcohol and other drug dependence to be involved in program delivery through employment as a peer worker. Those with lived experience often choose to work in the AOD sector, however, it is not considered peer work unless lived experience is a primary requirement for the role being filled. It's also important to note that the participation focus changes in that the role of a peer worker is to use their lived experience to directly support clients of a service.

Peer work focusses on building mutual and reciprocal relationships where understanding and emotional, social, spiritual and physical wellbeing and recovery are possible. This is specialised work which requires training and ongoing supervision from experienced providers. So, although lived experience is a primary footprint for both workforces, consumer participation and peer work refers to two different workforce roles.

It is important to recognise the differences between the role of a peer worker and someone who works in the health sector and also happens to have personal experience of AOD problems. Borkman (1976) describes how peer workers draw legitimacy from both their experiential knowledge and expertise as follows:

- Experiential knowledge - information acquired through the process of one's own recovery
- Experiential expertise - the ability to transform this knowledge into the skill of helping others to achieve and sustain recovery

In Victoria, the AOD peer workforce is recognised as an integral part of quality service delivery, resulting in many organisations formalising and integrating peer work into their service. SHARC and the AOD Peer Workforce Community of Practice have defined a 'peer worker' as the following: 'A peer worker utilises their lived experience of alcohol and other drugs, plus skills learned in formal training, to deliver services in support of others.'

Peer workers offer support to others who have shared experiences by:

- Facilitating authentic connections
- Sharing their personal experiences in a way that inspires hope
- Offering help and support as an equal, within a defined role
- Developing positive relationships that demonstrate the power and possibility of change

The peer role is often direct, either one-on-one or in group settings. They may engage in a wide range of activities and work including: individual and systemic advocacy; as consultants and advisers; health promotion; education; group development and facilitation; and/or research.

Evidence on the major benefits which the peer workforce brings to health outcomes and recovery has developed rapidly in the last decade, with some seeing it as one of the single most effective ways to develop and sustain a culture that stays focused on recovery practices (Health Workforce Australia, 2014; Repper & Carter, 2011). Peer workers can influence and change service culture and practice, and bridge gaps between the supports provided by other professionals. Benefits include: reduced social isolation; increased service access; improvements in social functioning; enhanced empathy and acceptance; reduced stigma; and increased feelings of hope.

SHARC's Peer Projects – Peer Workforce Development

At Peer Projects, a program of SHARC, we believe in the value of lived experience, one peer helping another, at all levels of the service system. Peer Projects provides a dedicated effort in AOD peer workforce development and operates as a sector resource for peer support initiatives.

What we do:

Peer workforce development and support

Peer Projects works alongside the Department of Health and Human Services (DHHS) to support the growth, development and sustainability of Victoria's AOD peer workforce in the treatment sector.

We deliver services under the SHARC Peer Worker Model, a framework that seeks to ensure a quality, consistent and sustainable peer workforce. Services include:

- SHARC Peer Worker Training
- Peer Worker Practice Supervision
- Organisational Readiness Training
- AOD Peer Workforce Community of Practice

Peer Workers in AOD

We facilitate the placement and support of Peer Workers within Victorian AOD services. We offer services to organisations in planning, recruitment, training and supervision.

Peer Workers in Justice

We also facilitate the placement and support of Peer Workers within the Justice System. These Peer Workers offer support to clients who are in the justice system as a result of their AOD use. For example: our Peer Workers are currently employed in providing support to parents engaged with the Family Drug Treatment Court (FDTC).

The Peer Projects Community

At Peer Projects we are actively building a community that supports the recognition and growth of peer work. Our relationships expand across states, countries and sectors as we work collaboratively with key stakeholders to define, support and advocate for the AOD Peer Work discipline.

"Peer workers engender hope, build supportive and respectful relationships that nurture and encourage recovery."-Peer mentor

Peer Educators in Harm Reduction

Harm Reduction Victoria – Peer education

Based on information provided by Harm Reduction Victoria, Melbourne

Harm Reduction Victoria (HRVic, formerly VIVAIDS) sees peer education as the heart and soul of its organisation and believes that people affected by a health or social issue have not only the moral right to address their issues, but also invaluable skills and perspectives to contribute.

When dealing with highly stigmatised behaviours such as illicit drug use and injecting drug use, peer-to-peer information sharing and safe behaviour modelling can have a high degree of credibility and effectiveness in reducing drug related risks. HRVic's peer education model balances the most reliable and appropriate health information from research with an 'insider' understanding of AOD use and its related harms.

HRVic researches what other educators, scientists and affected people understand about a health issue and uses this as a basis for discussion and 'reality checking' with peer participants involved in workshops and campaigns.

Peer education in its broadest sense is an organic process that occurs spontaneously during interactions between peer group members within their own networks. The kind of formal peer education that happens in workshops etc. is only going to be effective on a wider scale if it taps into or stimulates those organic peer-to-peer processes in the community. The rapid and widespread changes that drug users made to their injecting practices in response to the threat of HIV is an example of how effective peer education and community action can be, even though only a minority of the users involved in those changes would have attended any education or training sessions.

HRVic considers it beneficial for a well-trained and informed peer to facilitate peer education processes. This reinforces the notion of 'doing it for ourselves' and demonstrates that members of marginalised groups have the power within themselves to effect positive change.

Simply being a peer does not necessarily mean that a person has the skills to do research, facilitate a group or design a health promotion campaign. Campaigns and resources should be peer informed, but developed in partnership with people with appropriate skills. Most importantly, any resource or campaign should be considered a draft until it has been rigorously focus tested for accuracy, relevance, impact and credibility by peers, who should be independent of those who informed the development of the resource.

Peer Support Groups

Windana peer support groups

Based on information provided by Windana, Melbourne

Windana Drug and Alcohol Recovery Service operates a peer support group, located in St. Kilda at the Windana site. The groups run for 90 minutes each week and are open to AOD dependent people who want to recover and are not intoxicated at the meeting.

The peer support groups discuss the ups and downs of AOD use and the challenges of recovery and relapse. Each person shares their story and is provided with feedback and support or challenged by other members of the group. All three groups are facilitated by a paid peer worker whose role is to give feedback, keep the discussion on track, maintain a safe space, be a support for those in need, and act as a role model.

The peer worker is employed as a peer group facilitator. The role has a specific position description, monthly supervision and professional development opportunities.

Peer Workers

Peer workers at Banyule Community Health Centre's AOD service

Based on information provided by Banyule Community Health

Banyule Community Health (BCH) provides a range of services including withdrawal support, counselling, and support groups to individuals, couples, children and families affected by gambling, problematic AOD use, mental health issues, family violence and other issues.

Banyule regularly employs AOD peer support workers who are able to draw on lived experience of problematic substance dependence and mental health issues in order to engage in a meaningful way with clients.

Peer workers have become valued members of the AOD workforce. Within BCH's position description for a peer worker role, they list the qualities they believe peer workers will bring to their organisation.

Peer Support workers within this context are not merely tokenistic. They work closely and collaboratively with the counselling program and other teams at BCH to deliver a program which is welcoming, responsive and flexible. BCH recognises the unique needs and development of a peer workforce and offers considerable training and supervision to support staff in these roles.

Peer volunteers at SHARC's Family Drug Help

Based on information provided by Family Drug Help, Melbourne

Family Drug Help (FDH) is a peer-based service of SHARC that provides support to families of people who experience problematic substance use. A key service is the telephone helpline, staffed by people who are family members of substance users. The Helpline Coordinator advertises through Volunteers Victoria, social media and SHARC's own service users to recruit interested people to undergo training to become FDH volunteers. FDH uses a peer based model, with applicants required to have lived experience of AOD use in the family, allowing them to have a greater understanding of caller issues.

Applicants are screened for suitability and successful applicants undergo 30 hours of training. They are given a 3 month probationary period and supported through their first calls by the Coordinator. Once a volunteer is confident in answering calls, they usually work half a day per week on the helpline. All volunteers are asked for an initial 12 month commitment, and many stay on for several years. The Coordinator provides ongoing support and training. Volunteers are given access to debriefing when caller issues trigger personal issues.

The volunteers bring passion and enthusiasm at being able to support callers and 'make a difference' to other families.

Peer support mentors in justice

SHARC recruits, trains and supervises the peer support mentors who work in the justice system. Our peer support mentors have been a part of the Family Drug Treatment Court (FDTC) program since April 2015.

> *"As a peer support mentor I'm able to lead by example and assist parents in achieving their recovery goals. By virtue of my lived experience, I am able to guide and support parents through the court process and assist them with tools to access recovery" – SHARC peer support mentor*
>
> *"SHARC's peer support mentors have made significant contributions to the Court's understanding of the lived experience of addiction, which in turn allows us to provide a program that is more attuned with the needs of our participants." – FDTC staff member*

The FDTC: operating within the Family Division of the Children's Court of Victoria in Broadmeadows and Shepperton, the FDTC is a judicially monitored, therapeutic 12-month program conducted in a supportive, non-adversarial environment. The program seeks to engage parents whose children have been taken into care due to parental substance misuse or dependence, with the aim of achieving safe and sustainable family reunification.

What are peer support mentors? Peer support mentors utilise their lived experience of alcohol and other drugs, plus skills learned in formal training, to deliver services in support of others.

Peer support mentors provide direct, one-on-one and group support to FDTC participants. Their role is to positively mentor participants whilst they are going through the program, offering genuine empathy, understanding and practical support.

What can a peer support mentor offer?

- Provide emotional and practical support
- Assist participants to navigate the journey ahead
- Offer support as an equal, within a defined role
- Share their personal experiences in a way that inspires hope
- Promote self-advocacy and empowerment
- Support expansion of social and community supports
- Understand, because they've been there

> *"They are the best thing…. they have lots of insight and information" – FDTC parent*

See *Appendix 10* Peer Mentors in Justice brochure.

Experiential workers

Many alcohol and other drug agencies employ workers who have personally experienced substance dependence. Some agencies prefer to employ experientialists and have 'personal experience' as a key selection criterion. Other agencies have formal or informal practices of welcoming experientialists amongst their staff or keeping a balance between experientialist and non-experientialist workers.

Although the employment of staff with personal experience adds a richness to service delivery and may even contribute to improved services, this is by no means a replacement for active consumer participation practices. An experientialist becomes 'the professional' when employed: they are paid by an organisation, which may potentially create bias. Often the experientialist worker has not previously been a client of the service by which they are employed, and they may be far removed from the everyday struggle of the drug-using life and out of touch regarding current issues for service users.

Consumer Helpers

APSU Lived Experience Applied (LEAP)

APSU delivers a training course for people who are in a stable period of 'recovery' and/or have achieved significant treatment goals who wish to help others with their 'recovery' as peer helpers. The training covers topics such as phases of recovery, stages of change, boundaries and ethics, risk assessment, relapse prevention and self-care.

After completing the training, participants are encouraged to undertake voluntary peer help in a mainstream AOD service. Many of these peer helpers then go on to formally study in the AOD area and subsequently gain employment. Others feel confident enough to go on to study in other fields or gain voluntary or paid employment outside of the sector. Some graduates become part of the APSU Speaker's Bureau or take up other consumer participation activities. Feedback is obtained regularly from participants.

See *Appendix 11-13* for the Role and Responsibilities of a Peer, LEAP Placement Agreement and the LEAP evaluation form.

Sharing lived experience

APSU Speaker's Bureau

APSU maintains a database of people with personal experience of substance use who are able to speak on various AOD related topics to community groups, schools or professionals.

Requests for speakers are received and APSU matches the most appropriate person from the database. The speaker is then briefed on the requirements of the talk and the likely audience and assisted in developing their presentation. Particular attention is paid to ensuring that the speaker does not relay too much of their personal story, but rather emphasises their opinion about service provision and policy based on their own and others' experiences.

An inexperienced speaker is accompanied to the talk by an APSU staff member and debriefed after the session. An agreed fee is negotiated for the speaker depending on the amount of time spent and preparation involved.

Consumer consultants

Consumer consultants are the mainstay of consumer participation in the mental health sector and have been working across the mental health services in Victoria for many years. Although their role is sometimes unclear, consultants act as a liaison between patients and clinical staff. Their role may involve helping patients with complaints, explaining the treatment process, or assisting clinical staff in providing the best possible care for patients. Consumer consultants can sometimes walk a fine line between the patients, whose interests they are there to represent, and the service that employs them.

Staff selection

Service users have valuable input to offer in relation to the recruitment of staff and have successfully been incorporated at times into the staff recruitment process in mental health services (Grimshaw, 2003). Benefits include improving relationships between services and service users, as well as having a greater level of support for consumer participation. Unfortunately, consumer participation at this level occurs very infrequently, with only 20% of AOD service providers saying they would be willing to include service users in staff selection processes. This differs considerably from the opinions of service users, with over 50% saying they would be willing to participate in this type of activity (Bryant, Saxton, Madden, Bath, & Robinson, 2008b). Service providers gave the following reasons for the lack of participation: they were 'concerned about the practicalities', 'felt that consumers were inadequately skilled' or 'were unsure of the appropriateness or value of having service users involved'.

Involving service users in staff selection requires planning, but it is possible to achieve. There are several ways to involve service users in staff selection, all of which require a level of training, and may also require educating staff of the potential benefits of this practice. Consumers may be involved in deciding upon a position description for required staff, developing interview questions and participating in the interview and selection process.

SHARC service users in staff selection

SHARC has enshrined in its recruitment and HR policies its commitment to including consumers in the interview and recruitment processes of staff. It is a requirement that each selection panel for any staff position include a current service user.

SHARC has developed and refined the procedures and supports which allow this to happen successfully.

After trialing the process in the recruitment of the Chief Executive Officer in 2006 and again in 2008, plus the recruitment of the Peer Helper Campaign Coordinator (APSU) and the Recovery Support Service Manager, again in 2008, the following process has been adopted.

Identification of the consumer representative

If the position is program specific, the program manager may invite expressions of interest from consumers or may nominate a relevant person. Where the position is relevant across SHARC e.g. the CEO, each program manager identifies a potential representative, and they all decide among themselves who would be the best to represent this group.

Briefing of the consumer representative

A thorough briefing is provided to the consumer, explaining the position being interviewed for, its roles and responsibilities, as well as what is expected of the consumer during the interview. Being in an interview panel can be as daunting for the interviewer as the interviewee. This briefing may be provided by the CEO, a program manager or the Board Chair, depending on the position being interviewed for.

Short listing

Where possible the consumer representative should be involved in the shortlisting of candidates.

Interview process

Care should be taken that the consumer gets opportunity to ask questions of the candidates and not just be in an observer role. Likewise, it is important to support and encourage the consumer to have meaningful input into the final decision making.

Debriefing

Once the recruitment process is complete, it is important that a debriefing session be conducted with the consumer.

Quality assurance

Having quality assurance processes in place is an essential part of securing and retaining Quality Accreditation. This is an important opportunity for service providers to directly involve service users in the evaluation of the effectiveness of their programs.

SHARC service users in the Quality Accreditation process

In 2007 SHARC began the process of gaining accreditation through Quality Improvement and Community Services Accreditation (QICSA). A large number of quality standards require responses and verification before an agency can be accredited. All SHARC staff were required to participate in providing feedback and input for the standards. As one of its program areas, SHARC runs a Recovery Support Service (RSS) for young people. The young people of the program were also given the opportunity to become involved. Every fortnight over a period of several months a meeting was held with the RSS manager and the service users. The QICSA process was explained and at each meeting, service users were asked to comment on the relevant standard. Answers were recorded and formed the basis of the final report, along with staff and management responses.

The benefit of including service users in the process conveyed an important message that service user input was valued. The young people at RSS felt personally valued and their views were considered relevant and worthwhile. The organisation had the benefit of gaining another ‘outside’ perspective on their processes, and the inclusion of service users in such a formal process over a long period of time led to greater consumer participation within the organisation overall. The inclusion of service users on staff recruitment panels and the formation of a service user group were a direct result of this process.

Strategic planning

Consumers can be involved in strategic planning for an organisation or program area. It is essential that service users receive some preparation before attending a planning day, or that the day is designed with service users in mind. Although the best method for service users to contribute to strategic planning is to attend personally, if an organisation does not feel confident to involve service users or there is resistance, then other methods can be used e.g. surveys, focus groups and other feedback conducted prior to planning.

SHARC consumers in strategic planning

SHARC management regularly invites its consumers to be a part of its strategic planning days. Service users from each service area are invited by the manager of that service area. Consumers are assisted with transport, are made to feel welcome on the day and their views and opinions are taken seriously.

Salvation Army – focus group for strategic planning

Based on information provided by Salvation Army AOD Services, Melbourne, and APSU’s involvement in this project

A focus group was held to provide clients and ex-clients of Salvation Army AOD services with the opportunity to contribute to strategic planning in 2008. APSU sent invitations to anyone on their database who had used Salvation Army AOD services and offered remuneration. The focus group was held at Turning Point during the day.

The focus group was jointly facilitated by the APSU manager and the Victorian coordinator of the Salvation Army AOD services. It was felt that the presence of an authority figure such as the coordinator would demonstrate to participants that their views would be taken seriously. Feedback was collated and sent to all members of the Salvation Army leadership group who were working on the strategic plan. One of the main ideas that came out of the focus group was the need for a greater connection between all Salvation Army services. Although participants were informed of the strategic planning process and the aims of the focus group, there was no feedback to participants after the process had finished. The Salvation Army acknowledged that this could be improved next time, however, the involvement of consumers was a very positive experience and it is looking into holding service user focus groups in the future to contribute to program review.

PARTNERSHIP LEVEL

In a partnership there is a move towards joint decision making. Consumers and services jointly own the process and outcomes of a project. Although using peers in service delivery can be considered a partnership activity, peers often do not have equal say in service delivery. This section will focus on consumer involvement in committees.

Consumers on committees

When consumers participate in decision making processes with equal say (equal opportunity to take on valued roles and vote if applicable), they are in partnership with professionals. If there is only one consumer amongst many professionals, the consumer voice is reduced and it is questionable as to whether this is a true partnership. Nevertheless, one voice is preferable to no voice at all and this will be referred to as partnership in the following examples.

Another way of producing partnership is having a committee (perhaps an advisory committee) made up entirely of consumers, which has ‘equal’ say with professional decision making bodies in an organisation or process.

One of the challenges of consumers being on committees is the training or experience required to meaningfully participate. Additionally, because the balance of power usually lies firmly with the professionals, it is always best to have more than one consumer on a committee for alliance and support. A second participant can continue the role of communicating the consumer perspective if the first consumer has to pull out of the committee for any reason.

Consumer representatives

A consumer representative is just that: someone who represents the consumer viewpoint. Ideally, a consumer should be in touch with a base of other consumers to be a true representative. This group could be a service user group or a more informal group such as the clients of a particular service.

It can be difficult for consumer representatives to truly represent a group of consumers. However, many consumers, having had training or contact with other consumers over the years, are able to incorporate others’ ‘stories’ into their views and think in broad terms about AOD issues and service delivery. It is for this reason that these consumers are able to fulfil the consumer representative role despite having no formal ties with large groups of consumers.

Consumers on organisational committees

APSU Advisory Committee

The APSU Advisory Committee represents and advocates for the interests of people in Victoria who use AOD services, personally or by family association and/or friendship. This is achieved via the provision of advice, guidance and knowledge to the service manager, participating in APSU activities as required, assisting the manager to evaluate the effectiveness of the services, and providing input to strategic planning.

Terms of reference for the Advisory Committee outline the meeting procedure, responsibility of members, SHARC's responsibility to the committee and a grievance procedure. These terms are reviewed every two years. The committee is made up of two-thirds people with personal or family experience of AOD service use and one- third relevant service providers.

The committee meets once every two months, A meeting is only held when there is a quorum of two service users and one provider. Each participant is expected to attend at least three meetings a year to provide conceptual input and leadership. SHARC's CEO attends twice a year and is responsible for the ongoing resourcing of the committee.

Members are remunerated financially for their time. Participation in the APSU Advisory committee is considered an opportunity from which further opportunities may arise. This pivotal role is one that impacts substantially on the development of APSU and is greatly desired, evidenced by the significant numbers that respond when these positions are advertised.

To resource the committee and ensure that members are adequately informed takes planning and time. A monthly report of activities is compiled, agenda prepared and previous minutes sent a week prior to the meeting. Any publications developed outside of the APSU newsletter are sent for comment a fortnight prior to a meeting.

Consumers on boards of management

SHARC Board of Governance

Based on information provided by SHARC, Melbourne

Self Help Addiction Resource Centre (SHARC) has in its constitution the requirement that two-thirds of the members of the Board of Governance must be 'experts by experience'. This is written into the SHARC constitution:

22.1 The Board of Directors shall consist of nine positions comprising:

22.1.1 Six positions elected from the persons who are ordinary Members of the Association provided always that such ordinary Members are 'experts by experience' as defined in Rule 2.1.3; and

22.1.2 Three additional elected positions, who are ordinary Members of the Association, but not 'experts by experience' as defined in Rule 2.1.3; so as to complement the skills, experience and expertise of the other Members of the Board.

2.1.3 'Experts by experience' means people that have been directly affected by addiction related problems and includes people in recovery from addiction, family members who have lived with addiction problems and with the demands of recovery from addiction, as well as adult children who have experienced the effects of parental addiction problems, and people who have lost a loved one to addiction.

Consumer representation on external committees and reference groups

Sometimes organisations, programs and projects are unable to source consumer representation from their own networks. Part of the role of APSU is to provide consumer representation and advocacy on reference groups and advisory committees.

There are times when it is appropriate to have a representative from APSU or Harm Reduction Victoria on a committee or reference group. This may be particularly the case when the project is short term or when there is not enough time to recruit an appropriate consumer. Clearly an individual employed in an AOD advocacy role with a contact base or membership is more likely to be a representative than a consumer who has no contact with other consumers. For example, APSU consults with its membership when working on particular systemic issues, whilst delivering training or contributing to policy. When combined with an insider's knowledge of the service system, an AOD advocate's participation in committees or reference groups can be meaningful.

CONTROL LEVEL

At this level of participation, consumers have control over decision making and resources.

Narcotics Anonymous

Narcotics Anonymous (NA) is an international, community-based association of recovering drug users with more than 43,900 weekly meetings in over 127 countries worldwide (Narcotics Anonymous World Services website).

Membership is open to all drug users, regardless of the particular drug or combination of drugs used. Narcotics Anonymous provides a recovery process and peer support network that are linked together. Members share their successes and challenges in overcoming active addiction and living drug-free, productive lives through the application of principles contained within the twelve steps and twelve traditions of NA.

Narcotics Anonymous strives to be entirely self-supporting through member contributions and does not accept financial contributions from non-members. Based on the same principle, groups and service committees are administered by NA members, for members (Narcotics Anonymous World Services website).

The primary service provided by Narcotics Anonymous is the group meeting. Each group runs itself based on principles common to the entire organisation, which are expressed in NA literature. Most groups rent space for their weekly meetings in buildings run by public, religious, or civic organisations. Individual members lead the NA meetings while other members participate by sharing their experiences about recovering from drug addiction. Group members also work together to perform the activities associated with running a meeting.

In places where a number of NA groups have had the chance to develop and stabilise, groups elect representatives to form a local service committee. In some countries, especially those where NA is well established, a number of local/ area committees come together to create regional committees. These regional committees handle services within their larger geographical boundaries, while the local/area committees operate local services.

An international delegate assembly known as the World Service Conference provides guidance on issues affecting the entire organisation. Primary among the priorities of NA World Services are activities that support emerging and developing NA communities and the translation of NA literature (Narcotics Anonymous World Services website).

Harm Reduction Victoria's Committee of Management

Based on information provided by Harm Reduction Victoria, Melbourne

HRVic's Committee of Management (Board) is made up of nine members elected at an annual general meeting, plus three positions seconded from other community organisations or networks that support the aims of our organisation. The constitution ensures that members of the drug user community will hold at all times a majority on the Committee of Management. Casual vacancies are co-opted by the Board, keeping the majority of peers intact.

Staff are recruited by transparent selection processes and are required to have the skills, experience and qualities appropriate for the position. For peer-based positions, such as educators working with drug users, this includes a significant, lived experience of the issues that affect people who use illicit drugs. All employees are required to support the mission and values of the organisation.

As a peer based organisation, HRVic understands the importance of service user participation and regularly seeks to involve its own service users in governance structures, project- steering committees, workforce, consultations, focus groups, strategic planning and advocacy activities.

B. Consumer involvement in professional education and training

Studying the resources available to support consumer participation, there is little reference to the role of consumers in the education of professionals working in the areas of health, mental health, housing or AOD treatment.

There are two aspects of educating workers:

Consumer participation

The first aspect of educating workers is to train professionals in consumer participation. There are many professionals involved in the treatment of AOD service users: doctors, nurses, psychologists, social workers, welfare workers, AOD support workers and many others. As well as educating the existing workforce about consumer participation, all professionals undergoing training in the AOD field should be made aware of consumer participation practices. As the AOD sector is now raising its professional standards by requiring all workers to undergo a minimum educational standard, it seems reasonable that this standard include a basic knowledge of consumer participation.

The consumer perspective

The second aspect is that of providing the 'consumer perspective' to the formal training arena. Instead of considering learning from the point of view of the expert, the student/trainee has input from service users who are able to provide insight and learning on 'how it is for consumers'. This rarely involves the use of detailed personal stories but rather the use of brief anecdotal experiences of many consumers in presenting a key message. Several examples have shown that using consumers in key educational roles has benefits that include enhanced/less-stigmatised attitudes towards consumers, a greater willingness to include consumers in participatory roles (Happell & Roper, 2001) and encouraging practitioners to think of the consumer before acting in certain, potentially harmful, ways.

Often the role of consumers in providing a consumer perspective to professionals in mental health and AOD is largely limited to 'one-off' sessions or guest lecturing. While necessary, unfortunately this activity is at the lower level of participation, perhaps that of 'consultation'. A true partnership of consumers in the education and training of staff would entail consumer involvement in the development and delivery of course material.

Involvement of service users in medical students' education

NSW Health, 2015

In 2001, Wentworth Area Health Service Centre for Drug and Alcohol Medicine was approached to provide education to first year medical students from the Western Clinical School in NSW. Consumers involved were required to be stable and have a variety of treatment experiences and social circumstances. Western Clinical School provided subsidised transport costs and a gift voucher reimbursement. WAHS provided support for the service users and a brief overview of AOD issues to the medical students. Service users told their 'stories' to the medical students in a supported environment.

The clinical school found that the provision of quality education to medical students was meaningful to their future practice and that the service was promoted as a legitimate, quality service. Clients had the opportunity to participate equally in the promotion of alcohol and other drug interventions. They were also able to express themselves within the context of health in a respectful environment. This provided them with an opportunity to view themselves and their personal experiences as valuable.

Consumers training professionals in consumer participation

APSU, staffed by consumers, provides workshops for organisations and their staff to increase awareness and knowledge of how to develop consumer participation practices. APSU has also delivered numerous presentations to AOD conferences on this topic.

The Consumer Participation training project, funded by the Federal SMSDGF program was conducted by APSU and Taskforce Community Agency from 2013-2017. A comprehensive training program for AOD staff, managers and board members, workshops were conducted across Victoria,

The course was largely based on APSU's Straight from the source: A practical guide to consumer participation in the Victorian alcohol and other drug sector.
Topics included:

- Introduction to CP
- History, benefits, evidence, barriers and meaningful participation
- Principles of CP
- Family participation

The project culminated on a one-day forum. The CARE (Consumer; Action; Recovery; Empowerment) Ideas Exchange took place in Melbourne in May 2017. Over 90 people, from across Victoria and interstate, attended this full- day event focusing on the role and future of consumer participation in the AOD sector.

Consumers were closely engaged at all levels of the project including developing content, delivery of training workshops and presenting at the forum.

See Appendix 15 for information and promotional material related to this project.

Family providing the consumer perspective in a 'guest lecturer' capacity

SHARC's Family Drug Help (FDH) is a program staffed by people who have personal experience with a family member's addiction and are professionally trained to support families of people who have problematic AOD use. As part of this program FDH provides education for professionals in AOD agencies, medical practitioner networks, conferences, workshops, community information networks, volunteer networks, rehabs, clinics, prisons and courts. This education provides a family perspective on drug use.

When FDH receives a request for an educational session, they select an appropriate speaker from amongst staff, the steering committee or trained volunteers according to the particular educational session requirement.

The FDH educator presents material in general terms rather than 'telling their story', as this can be voyeuristic and can leave educators feeling vulnerable and exposed. Some personal anecdotes may be used to illustrate a point.

If the person selected is not a staff member, FDH provides training and support by allowing them to observe someone else's presentation beforehand; attending their presentation; and providing debriefing afterwards.

Feedback from professionals receiving the education is very positive. Many are grateful to have been presented with the 'other side of the story'. Others say they feel more confident to explore the family situation.

Involvement of service users in dual diagnosis training

Information obtained from APSU's involvement in this project

The Victorian Dual Diagnosis Education and Training Unit (ETU) involves service users and family in the delivery of its online training. This is in line with Service Development 5 of the Dual Diagnosis Key Directions and Priorities for Service Development: 'consumers and carers are involved in the planning and evaluation of service responses' (Victorian Department of Human Services, 2007). Working with APSU and the Victorian Mental Illness Awareness Council (VMIAC), the ETU set up sessional positions for dual diagnosis experiential educators.

The goal of this initiative was to recruit and mentor consumers as they completed the online dual diagnosis course, the online facilitators' course offered by the ETU, and delivered training units to professionals. The online dual diagnosis training is for the Mental Health, AOD and Psychiatric Disability Rehabilitation and Support Services workforce as a means of developing dual diagnosis capability. Once training is completed, consumers then go on to become experientialist facilitators and they co-facilitate sections of the online course. The maximum time for participation is two years.

Recruitment was facilitated via APSU and VMIAC.

A position description was developed as a result of the collaboration of APSU, VMIAC and the ETU. The selection criteria were:

- Experience of co-occurring AOD and mental health issues
- Current capacity to carry out all required functions of the role
- Commitment to completion of training units and delivery of at least three rounds of training
- Demonstrated ability to complete the online facilitation course
- Demonstrated ability to communicate knowledge to a group.

All applicants submitted an application addressing each of these criteria. They were then shortlisted for interview and two applicants were appointed.

These experiential educators are per sessional training payment. Support and mentoring is a collaborative effort of APSU, VMIAC and the ETU and will be provided while the educators complete online training and delivery of online sessions.

See *Appendix 16* for Job Description

C. Consumer involvement in policy development

Consumer participation occurring in the organisational domain can have an enormous capacity to improve services. However, this capacity is even greater when systemic change is initiated through consumer involvement in policy development.

The principles required for meaningful policy participation are the same as for those in the organisational domain (see *Principles and practices* in Part One and *Organisational committees*).

All consumers involved in policy development require sufficient training and support to effectively participate. Token participation is to be avoided by clearly defining the role(s) of the consumer(s) in the policy development activity and involving consumers as early as possible in the process.

CONSULTATION LEVEL

Victorian AOD treatment reform advisory groups

In 2012 APSU was engaged by the Victorian Department of Health (DH) to work with service users, families and carers to provide input on the reform directions. The Advisory Groups were established into eight groups: Intake and Assessment; Withdrawal (residential and non-residential); Counselling; Care and Recovery Coordination; Residential Treatment; Forensic Services; Managing Change; and Youth.

APSU put out a request for expressions of interest to participate on the Advisory Groups and received an over-whelming response and genuine interest from across the state.

Everyone saw this as an opportunity to have a say on the treatment sector, in the hope that changes would occur so that others didn't have the same or similar experience when accessing or receiving services. From the 38 expressions of interest, APSU recruited eight family members and eight service users, one family member and one service user to represent consumer views on each of the eight groups.

All participants were offered Experts by Experience training facilitated by APSU. Over the course of nine months each group met at least 4 times for 2-3 hour periods. All minutes from each group were placed in the public domain on the DH & Victorian Alcohol and Drug Association (VAADA) websites.

Upon conclusion of the advisory groups, APSU held a focus group with the participants. Overall feedback was positive, with participants reporting that they felt their views were considered and heard.

Treatment Principles - Consultation

In addition to the Reform Advisory Groups APSU sought the views, feedback and opinions of service users and family/carers on the proposed treatment principles.

The feedback was sought through two methods - electronic survey questionnaire and face-to-face forum with family/carers. Both were conducted in the same format:

- Participants were provided the proposed principles consultation paper
- Participants were asked if they thought the principles were appropriate
- Participants provided comment on the principles and the key concepts outlined within the consultation paper.

PARTNERSHIP LEVEL

When policy is jointly developed between government and consumers there is said to be partnership.

Development of the Victorian AOD Charter

The development of the Victorian AOD Charter began in the wake of the Victorian Charter of Rights and Responsibilities (2006). During 2006 and 2007 the development of this charter was a key performance indicator of the funding agreement between APSU and the Victorian Department of Human Services (now Department of Health & Human Services). The development of this charter used the material from five focus groups that were run by APSU from 2006 to 2007 as well as the materials obtained during the 2004 *Speaking Out* project.

A brief was submitted to DHS outlining the objective, method and outcomes. The literature and materials underpinning the development of this charter included the following:

Association of Participating Service Users 2004, *Speaking Out, Rights and Responsibilities for Users of AOD Services*, Self Help Addiction Resource Centre, Melbourne

Department of Health and Ageing 2005, *Draft of National AOD Charter*, Commonwealth Government of Australia, Canberra

Department of Justice 2005, *The Human Rights Consultation Committee: Have your Say About Human Rights in Victoria* State Government of Victoria, Melbourne

Department of Justice 2005, *Rights Responsibilities and Respect*. State Government of Victoria, Melbourne

Justice Department, Safer Communities Division, 2004, *Draft National Quality Standards* for Substance *Misuse Services*, Justice Department, Scotland

Victorian Charter of Rights and Responsibilities (2006)

The International Covenant on Civil Political Rights (1966)

Sixty people attended the focus groups held at different venues in regional and metropolitan Victoria. Venues included SHARC, Victorian Association for the Care and Resettlement of Offenders (VACRO), Peninsula Drug and Alcohol Program (PenDAP), and Ballarat and District Aboriginal Cooperative. Prior to the focus group, people were sent reading material and an agenda of proceedings. Upon completion, focus group participants were sent compiled notes for comment. Once the final draft was completed, this was also mailed out for comment.

Recruitment was achieved via APSU membership and contacts from local host agency. Participants received a small fee and lunch was provided.

Literature and materials were compiled in accordance with six common themes found in the materials obtained from the focus group. These were:

- The right to equal treatment.
- The right to privacy.
- The right to a fair hearing.
- Humane treatment when deprived of liberty.
- The special rights of members of ethnic, religious and linguistic minorities.
- The right to complain.

A draft was sent to all participants and to relevant services for comment. The charter was submitted to DHS for input and a final copy was agreed upon in November 2007.

See Appendix 2: Victorian *AOD Charter*.

D. Consumer involvement in research

Research has long been in the hands of the 'expert' or the researcher. It is generally the funding body or organisation that decides on the topics or areas that are to be researched, how that research will be conducted and who will conduct it. Consumers often have a different perspective on what is important to research as well as the outcome measures that are important when assessing different treatment modalities.

The most thorough approach to involving consumers in research is termed 'community-based participatory research', 'participatory research' or 'participatory action research' and has long been recognised as a way of developing more relevant responses to health care issues than traditional research is capable of providing (Horowitz, Robinson, & Seifer, 2009; Macaulay, et al., 1999).

It involves consumers being equal partners in deciding priorities for research, the methods used and the analysis and dissemination of the results. In this way, research is able to be more relevant to the people who are being researched or studied.

Community based participatory research is said to have the following benefits (Adapted from Horowitz, Robinson, & Seifer, 2009):

- Diverse skills, knowledge and expertise, which lead to new hypotheses and approaches.
- Increased likelihood that high priority issues are addressed in a manner that recognises and incorporates key contextual factors and influences outside the clinical setting.
- Improved quantity, quality validity and reliability of data.
- New analytical questions posed by community.
- More accurate and culturally appropriate interpretation of findings.
- Research is more likely to lead to tangible health and community benefits.

While participatory research is at the highest level of consumer involvement, consumers may also contribute to research by defining outcome measures, commenting on methods and by assisting with data collection.

CONSULTATION LEVEL

Drug users consulted on quality of life indicators

Adapted from De Maeyer, Vanderplasschen, & Broekaert, 2008

Many variables have been used to measure the effectiveness of treatment interventions for substance users, such as the amount of drug use, criminal activity and employment. However, drug users themselves have not often been consulted on what is important to them in treatment outcomes. Although ‘quality of life’ has sometimes been used as an outcome measure for AOD research, it is almost always defined by professionals. Researchers in Belgium therefore sought to establish a drug user perspective on quality of life.

Nine focus groups were conducted in various treatment facilities in Belgium involving 67 participants, most of whom were men. Participants received remuneration in the form of a supermarket voucher. The research found that drug users perceived quality of life to be about much more than just physical or mental health. Indeed, physical health was rarely volunteered by participants as a main factor in quality of life, and they cited other factors such as personal relationships, social inclusion, personal development, self-determination and rights as being more important to quality of life overall.

The findings of this research are consistent with the reasons why people often seek treatment; that is, because of problems arising from social and psychological concerns. It would therefore be reasonable to give more attention to these aspects of quality of life when considering improvements to service provision. This may increase access and retention of clients in treatment.

Consumer focus group to help plan methamphetamine approach bias modification research

Adapted from The Projects Explanatory Statement and APSU’s involvement

A world-first trial of “approach bias modification” (ABM) for people trying to cease using methamphetamine is being conducted by Monash University (2019). To ensure that the study protocol is as relevant and acceptable to participants as possible, aspects of the study are being reviewed by people with a lived experience of methamphetamine use and addiction treatment in the past.

APSU is responsible for organising and convening the focus groups to review two main aspects of the protocol: the images to be used in the ABM training and the schedule of tests and questionnaires participants will be asked to complete.

This being a research project, ethical approval had to be obtained for the study; APSU had to be registered and recognized as a research partner, and all focus group participants are required to sign a consent form.

All potential participants receive a plain English Explanatory Statement setting out what is involved; what the research is for; how the data will be stored; how to make a complaint; and what the level of remuneration is.

CONSULTATION/PARTNERSHIP LEVEL

Peer researchers at Burnet Institute

Based on information provided by the Burnet Institute, Melbourne

The Burnet Institute, one of Australia's leading medical research and public health institutes, conducts research into AOD use from a public health perspective.

The Melbourne Injecting Drug User Cohort Study (MIX), began in 2008 and continues today (Burnet Inst., 2019) It seeks to provide a longitudinal picture of injecting behavior both of heroin users and the increasing number of injecting amphetamine users. The results are intended to assist in forming appropriate AOD policy responses.

The MIX project involves the recruitment and follow-up of young injecting drug users. Data is collected by the AOD fieldwork team, a mixed peer/non-peer team. The team conducts outreach-based fieldwork with the support of a mobile van and collects information from people who use drugs across a number of Melbourne suburbs. The data collection (interviewing and some blood testing for HIV, hepatitis B and C) is the core task of the fieldwork team, but they also provide sterile injecting equipment, health education and referrals.

Peer researchers are recruited in several ways, including through networks developed during previous AOD research and through recommendations from other community workers or Needle and Syringe Program (NSP) workers.

Once potential peer researchers are identified, they are asked to write a letter of introduction and state why they think they would be suitable for the position. They are then invited to an informal interview, giving both parties the opportunity to see if the person/position is suitable. Burnet Institute's experience has been that the more successful peer researchers have their personal drug use in perspective – they may still be using, but not in a chaotic way. If people are still using in a chaotic way, the responsibilities of working on this project prove more difficult, and it is suggested that the peer comes back when their drug use is more controlled.

A peer researcher is required to have a range of other skills, including being comfortable with other people who use drugs and having a non-judgmental attitude about where people are at in relation to their drug use. Having specific networks of other drug users, e.g. from a specific ethnic or cultural background, is also an asset.

On-the-job training is provided in relation to conducting interviews and workplace safety. Peer researchers are provided with specific training in pre- and post-test counselling for HIV and hepatitis C. Field workers are also trained in taking blood from potential research participants, if that is required for the study they are working on.

Fieldworkers are given other opportunities to participate in research, including presenting at local conferences or meetings. Support is provided in helping people present the information they collect using various media such as writing articles for drug user- specific magazines.

New fieldworkers are provided with day-to-day supervision to ensure that they are coping with the demands of working in such a unique environment. Weekly supervision is provided for all fieldworkers (peers and non-peers) by a team leader, and there are opportunities for other more personal support if required.

Fieldworkers who are employed (peers and non-peers) are paid as per the relevant university award depending on their previous academic qualifications. There is no difference in the salary for peers and non-peers.

While peers working on the MIX project have limited involvement in study design, many of the current studies build on the learning achieved from peers involved in previous research projects. Peers are equally involved in the recruitment and the interviewing of participants. Fieldworkers participate in the research through identification and recruitment of potential participants and weekly participation in team meetings. They also contribute to new research questions from talking with research participants about issues that arise in their day-to-day lives.

It is essential to ensure that peer researchers are ready for this kind of job. It can be very confronting working closely with people who are still actively using drugs. Also, boundaries between workers and participants can be very blurred and need to be addressed.

CONTROL LEVEL

Consumer-led research – impact of pharmacotherapy costs

Information provided by James Rowe, RMIT Centre for Applied Social Research (Rowe, 2008)

This research project was led by Dr. James Rowe, Research Fellow, RMIT Centre for Applied Social Research, who, although not employed as such, identifies himself as a consumer. The project was funded by the Salvation Army and guided by a reference group made up of AOD service providers and the peer-run Pharmacotherapy Advocacy and Mediation Service (PAMS), a service of Harm Reduction Victoria.

The research was prompted by the need to gather evidence regarding the difficulty that consumers had in paying for their pharmacotherapy doses to support application to the Department of Human Services to assist with costs.

Interviews were conducted with 60 pharmacotherapy consumers who were also recipients of Centrelink benefits as their only source of income. These consumers were asked to fill in a survey in addition to being interviewed. A further 60 surveys were also administered to consumers who provided information on the impact of dispensing fees. The 120 consumers were accessed through four AOD services across Melbourne. The consumer-led design of the interview and survey questions provided a richness and relevance that may not have been otherwise obtained. As pointed out by James Rowe:

> *“Consumers are the true experts on the effects of dispensing fees and the way in which it affects them – without their input there is no way such a report could be done”.*

Finally, three dispensing pharmacists were also interviewed as to their views on the impact of dispensing fees on the client/pharmacist relationship.

The results demonstrated that the impact of dispensing fees on people who were receiving pharmacotherapy treatment in Melbourne was detrimental to consumers and their ability to enter the program and remain in treatment.

Australian Injecting and Illicit Drug Users League (AIVL) – Treatment Service Users Project

Adapted from AVIL, 2008

The Australian Injecting and Illicit Drug Users League (AIVL) is the national peak organisation for state and territory peer-based drug user organisations and represents issues of national significance for people who use or have used illicit drugs.

In 2005, AIVL conducted a consumer driven research project aimed at exploring the current practice of consumer participation in Australian AOD treatment services. In collaboration with the national Centre in HIV Social Research (NCHSR), AIVL conducted surveys and focus groups of service providers, service users and other relevant stakeholders to determine the levels of consumer participation in the AOD sector and the opinions of providers and service users about consumer participation.

The project was guided by a multidisciplinary advisory committee consisting of AIVL, NCHSR, the Department of Health and Ageing, Australian National Council on Drugs, clinical services representatives, three consumer representatives and other stakeholders.

The results of this project (Bryant, Saxton, Madden, Bath, & Robinson, 2008b) created a knowledge base about consumer participation in the AOD sector.

A prison-based participatory action research project

Adapted from Sullivan, Hassal, & Rowlands, 2008

Grendon Prison in the UK is a category B male prison in which all five wings are run as therapeutic communities (TCs). While Grendon Prison has less drug use than usual for a prison, relapse still occurs amongst members of the TCs. Any relapse requires prisoners to exit the TC and in fact the prison. Prisoners who were already acting as representatives of a Drug Strategy Group voiced their concern that the men in the TC needed extra support in order to remain abstinent.

The Drug Strategy Group listened to these concerns and asked the prison reps to show evidence of the need for extra support in relapse prevention. They also needed to demonstrate that this support would be acceptable to staff and prisoners in the TC, as some types of support were seen as being in conflict with the therapeutic community model.

The prison representatives were offered help by the Senior Research Officer of the prison, who assisted without removing the men's enthusiasm, or control. It was felt that 'insider' knowledge was important in this setting and could easily be lost if the research was taken over by professionals. Eight prisoner representatives and the senior researcher formed an action research group to examine possible relapse prevention models.

With guidance, the research group chose a survey as a method to determine the needs of the prisoners, then designed and developed the survey and administered it to all prisoners and staff. 53% of prisoners and 17% of staff responded. The group considered all the responses to the survey questions and an interim report was written. The report was presented to the Drug Strategy Group by the Senior Researcher (the prisoner members of the Research Group could not attend the meeting due to prison security issues). An outside agency had offered to provide a free trial relapse prevention course to the prisoners and it was decided that the Drug Strategy Group would accept the trial course and the Drug Research Group would evaluate its effectiveness.

The research group designed and administered the evaluation interviews, and a report was written and presented to the Strategy Group.

On the basis of the needs analysis and the evaluation of the trial course, prison authorities sought funding for a permanent relapse prevention course. At the date of writing the paper (2008), funds had not been granted.

A number of difficulties existed for the project. Firstly, security requirements in prisons left the prisoner representatives without computer access, limiting their ability to contribute to report writing and to the final research paper. It also limited their ability to present their findings at prison meetings. Secondly, although prison and clinical staff were invited to be part of the process by attending various meetings, few actually attended, leaving prisoners feeling ignored and unimportant.

Positive aspects of this project included a problem identified by those who would normally be the subjects of research. The prisoners attempted to solve the relapse problem by finding evidence and implementing a solution. As a result of this process, the prison representatives gained self-esteem, confidence, knowledge and skills, many of which are transferable to other areas of their lives. Despite the lack of cooperation from some staff, representatives felt a great sense of pride in their achievement.

> *"[The project] has given me a lot more confidence, it's given me a bit more responsibility, a sense of responsibility, not in stuff that I just do on [the project] but in other stuff... as well" – Prisoner*

Resources

CONSUMER PARTICIPATION

Publications

1. Consumer Focus Collaboration, 2000, *Improving Health Services through Consumer Participation: A Resource Guide for Organisations*, Department of Public Health, Flinders University, and the South Australian Community Health Research Unit, Commonwealth of Australia
   - A comprehensive and practical manual on consumer participation in general health services.
2. HomeGround Services and Rural Housing Network Ltd, 2008, *Consumer Participation Resource Kit*, Council to Homeless Persons
   - An easy-to-read manual on consumer participation in the Housing and Homelessness Assistance sector. Covers many issues relevant to the AOD sector.
3. NSW Health, (2005), *A Guide to Consumer Participation in NSW Drug and Alcohol Services*, NSW Department of Health, Sydney
   - A NSW-based guide to consumer participation in the NSW AOD sector. Some good Australian examples given.
4. Standing Conference on Drug Abuse, 1997, *Getting drug users involved*, SCODA, London, UK
   - A UK guide to participation in the AOD sector. Some interesting and innovative examples given.
5. Payne C, 2009, *'Hume Region Alcohol, Tobacco & Other Drugs Consumer & Carer participation Project'*, Goulburn Valley Health Service, Shepparton
   - An in-depth look at AOD consumer participation in Australia and Hume Region ATOD consumer participation activities and strategic plan included.
6. Hinton T, 2010, *Voices on Choices: working towards consumer-led alcohol and other drug treatment*, Social Action and Research Centre, Anglicare, Tasmania
   - An in-depth look at consumer participation in the UK and its lessons for Australia with recommendations for a consumer participation framework in Tasmania and Australia.
7. Uniting Regen 'Handy stuff', a list of resources for consumers found here: https://www.regen.org.au/images/ReGen/Handy-Stuff-FINAL-WEB.pdf

Organisations

SHARC/Association of Participating Service Users (APSU)

140 Grange Road, Carnegie, Vic 3163
Phone: (03) 9573 1736
Fax: (03) 9572 3498
Email: apsu@sharc.org.au
Web: www.apsuonline.org.au

Harm Reduction Victoria

128 Peel Street, North Melbourne, Vic 3051
Phone: (03) 9329 1500
Fax: (03) 9329 1501
Email: info@hrvic.org.au
Web: www.hrvic.org.au

Health Issues Centre

Level 5, Health Sciences 2, La Trobe University, Vic 3086
Phone: (03) 9479 5827
Fax: (03) 9479 5977
Email: info@healthissuescentre.org.au
Web: www.healthissuescentre.org.au

Victorian Mental Illness Awareness Council (VMIAC)

Building 1, 22 Aintree Street, Brunswick East, Vic 3057
Phone: (03) 9380 3900
Email: info@vmiac.com.au
Web: www.vmiac.com.au

APSU can provide practical assistance with all aspects of consumer participation in a number of ways:

- assisting in the development and implementation of policy
- offering education, training and support for people who wish to become involved, not only in peer roles but also in governance
- APSU’s membership of trained service users can be called upon to assist in providing consumers to form issues based advisory groups.
- APSU is able to provide training and support for consumer participants as well as opportunities to connect with other consumers in participation roles.
- the APSU Speaker Bureau can recruit consumer participants who identify as having a dual diagnosis.

To access these services or to discuss your needs, contact APSU via:

Ph: 03 9573 1736

Email: apsu@sharc.org.au

Youth

Organisations

Youth Support and Advocacy Services (YSAS)

Youth Drug and Alcohol Advice (YoDAA)

Phone: 1800 458 685
Email: advice@yodaa.org.au
Web: www.yodaa.org.au
Web: www.workingitoutwithyodaa.org.au

YSAS Head Office

1/131 Johnston St, Fitzroy VIC 3065
General enquiries: (03) 9415 8881

YSAS Feedback

Youth Participation Officer: YSAS, Level 1/131 Johnston Street, Fitzroy VIC 3065
Email: feedback&complaints@ysas.org.au

Headspace Collingwood YAC

Email: reception@collingwoodheadspace.org.au

Publications

1. YSAS – Get Involved Youth Participation https://www.ysas.org.au/youth-participation
2. Citizen Me! – Helps organisations, including government departments, meaningfully and effectively involve children and young people in their decision-making http://www.kids.nsw.gov.au/Publications---resources/Participation
3. Centre for Multicultural Youth Issues (2005). Considering consulting? A guide to meaningful consultation with young people from refugee and migrant backgrounds http://www.cmy.net.au/ sites/default/files/publication-documents/ Considering%20Consulting%20good%20 practice%20guide%202009.pdf

INDIGENOUS

Organisations

Ngwala Willumbong Cooperative Ltd

93 Wellington St, St. Kilda, Vic 3182
Phone: (03) 9510 3233
Fax: (03) 9510 6288
Email: reception@ngwala.org
Web: www.ngwala.org/

Victorian Aboriginal Community Controlled Health Organisation Inc. (VACCHO)

17-23 Sackville St, Collingwood VIC 3066
Phone: (03) 9411 9411
https://www.vaccho.org.au/

VACCHO provides training on Aboriginal Mental Health First Aid training for community members, organisations, and others who want to learn more about Aboriginal Mental Health First Aid. Visit the Cultural Safety webpage if you or your organisation would like to know more about the 14 hour (two day) Aboriginal Mental Health First Aid training session.

Further information found here: https://www.vaccho.org.au/educational/cs/

CULTURALLY AND LINGUISTICALLY DIVERSE

Publications

4. Department of Human Services, 2006, *Cultural Diversity Guide: Planning and delivering culturally appropriate human services*, Department of Human Services, Melbourne
5. Romios P, McBride t, Mansourian J, 2007, *Consumer Participation and Culturally and Linguistically Diverse Communities: A Discussion Paper*, Health Issues Centre Inc, La Trobe University, Melbourne
6. VAADA CALD AOD Project: Consultation report http://sharc.org.au/wp-content/uploads/2015/05/NEW-CALD-Report.pdf
7. Centre for Multicultural Youth Issues (2005). Considering consulting? A guide to meaningful consultation with young people from refugee and migrant backgrounds https://www.cmy.net.au/sites/default/files/publication-documents/Considering%20Consulting%20info%20sheet%202009.pdf
8. Multicultural Disability Advocacy Organisation http://www.mdaa.org.au/

Organisations and resources

Drug Info Multicultural Website

- Victorian multicultural AOD services directory
- Cultural competency training for organisations
- Research on CALD drug use and treatment

Website: http://www.druginfo.adf.org.au/multicultural/

Drug and Alcohol Multicultural Education Centre

Level 2, 619 Elizabeth Street, Redfern, NSW 2016
Ph: (02) 9699 3552
Email: admin@damec.org.au
Website: http://www.damec.org.au/

Centre for Culture, Ethnicity and Health

81-85 Barry Street, Carlton Vic 3053
Ph: (03) 9342 9700
Email: enquiries@ceh.org.au
Website: http://www.ceh.org.au

GAY, LESBIAN, BISEXUAL, TRANSGENDER AND INTERSEX

Organisations

Gay and Lesbian Health Victoria	www.glhv.org.au
People Living with HIV/AIDs Victoria	www.plwhavictoria.org.au
Rainbow network	www.rainbownetwork.net.au
TransGender Victoria	www.transgendervictoria.com
The ALSO Foundation	www.also.org.au
Victorian Aids Council and Gay Men's Health Centre	www.vicaids.asn.au
Way out	https://www.wayout.lgbt/
Switchboard	http://www.switchboard.org.au

DISABILITY

Publications

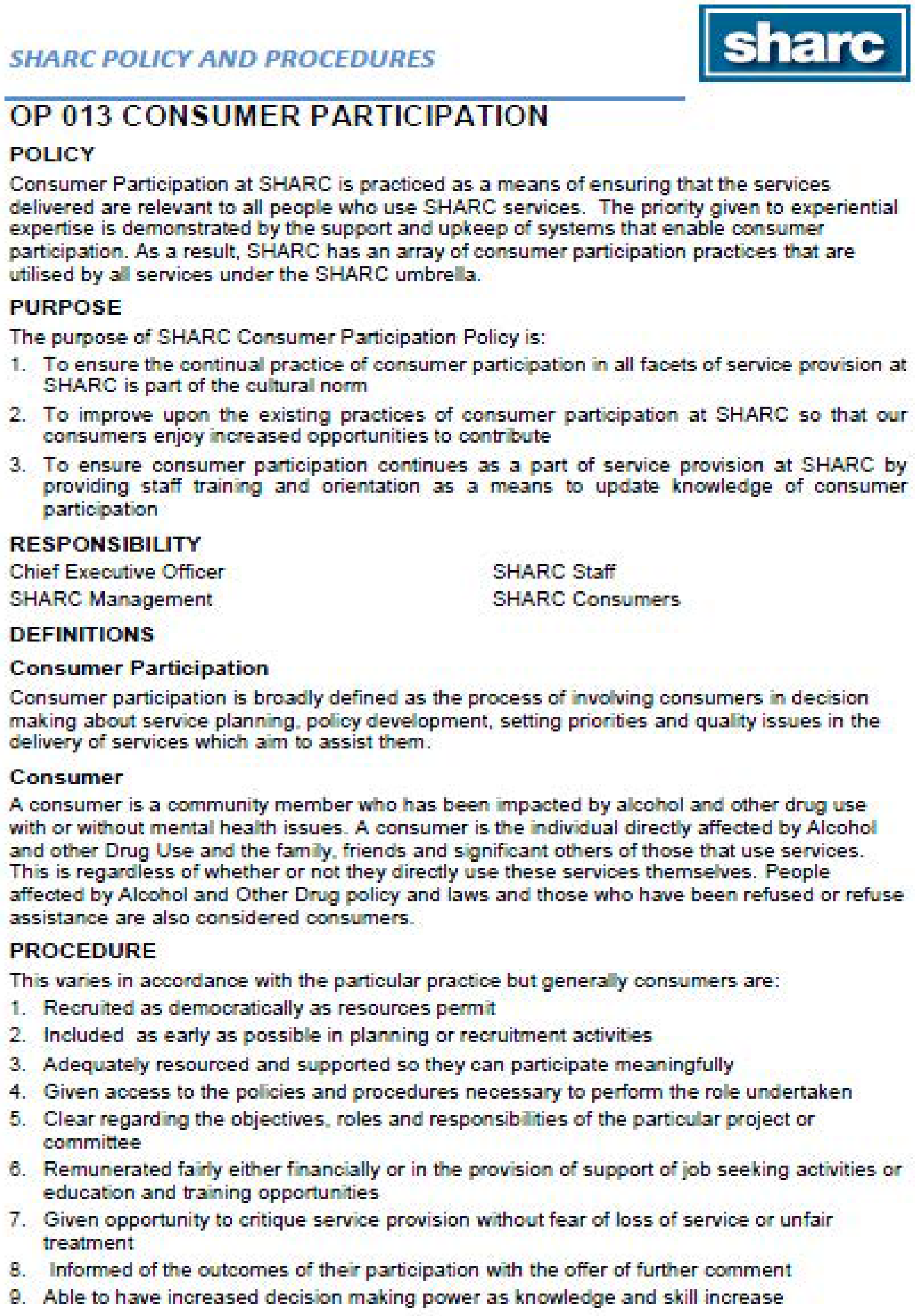
How to advise staff on disability awareness. Job Access, Australian Government website, http://jobaccess.gov.au

Access policy. Victorian Department of Human Services website, http://www.dhs.vic.gov.au/disability/ publications-library/access_policy

Aspirations of People with a Disability within an Inclusive Victorian Community. Victorian Department of Human Services website, http://www.dhs.vic.gov.au/disability/publications-library/aspirations_of_people_with_a_disability_within_an_inclusive_victorian_community

Appendices

Appendix 1: SHARC consumer participation policy



SHARC POLICY AND PROCEDURES

sharc

OP 013 CONSUMER PARTICIPATION

POLICY

Consumer Participation at SHARC is practiced as a means of ensuring that the services delivered are relevant to all people who use SHARC services. The priority given to experiential expertise is demonstrated by the support and upkeep of systems that enable consumer participation. As a result, SHARC has an array of consumer participation practices that are utilised by all services under the SHARC umbrella.

PURPOSE

The purpose of SHARC Consumer Participation Policy is:

1. To ensure the continual practice of consumer participation in all facets of service provision at SHARC is part of the cultural norm
2. To improve upon the existing practices of consumer participation at SHARC so that our consumers enjoy increased opportunities to contribute
3. To ensure consumer participation continues as a part of service provision at SHARC by providing staff training and orientation as a means to update knowledge of consumer participation

RESPONSIBILITY

Chief Executive Officer	SHARC Staff
SHARC Management	SHARC Consumers

DEFINITIONS

Consumer Participation

Consumer participation is broadly defined as the process of involving consumers in decision making about service planning, policy development, setting priorities and quality issues in the delivery of services which aim to assist them.

Consumer

A consumer is a community member who has been impacted by alcohol and other drug use with or without mental health issues. A consumer is the individual directly affected by Alcohol and other Drug Use and the family, friends and significant others of those that use services. This is regardless of whether or not they directly use these services themselves. People affected by Alcohol and Other Drug policy and laws and those who have been refused or refuse assistance are also considered consumers.

PROCEDURE

This varies in accordance with the particular practice but generally consumers are:

1. Recruited as democratically as resources permit
2. Included as early as possible in planning or recruitment activities
3. Adequately resourced and supported so they can participate meaningfully
4. Given access to the policies and procedures necessary to perform the role undertaken
5. Clear regarding the objectives, roles and responsibilities of the particular project or committee
6. Remunerated fairly either financially or in the provision of support of job seeking activities or education and training opportunities
7. Given opportunity to critique service provision without fear of loss of service or unfair treatment
8. Informed of the outcomes of their participation with the offer of further comment
9. Able to have increased decision making power as knowledge and skill increase

Appendix 2: Victorian AOD Client Charter

As an advocacy service that upholds the rights of people using Victorian alcohol and other drug (AOD) services, the Association of Participating Service Users (APSU) is happy to introduce this charter of rights and responsibilities. The charter is based on the knowledge and experience of 160 AOD service users who participated in focus groups held across Victoria. The creation of this charter, by people who use Victorian AOD services, has endeavoured to follow a democratic process. The implementation of this charter will contribute greatly to a fairer Victoria.

(Association of Participating Service Users)

Department of Health

health

Victorian alcohol
and other drug
client charter

Accessibility

If you would like to receive this publication in an accessible format, please phone 9096 5234 or email consumers@health.vic.gov.au

March 2011 (1006037)

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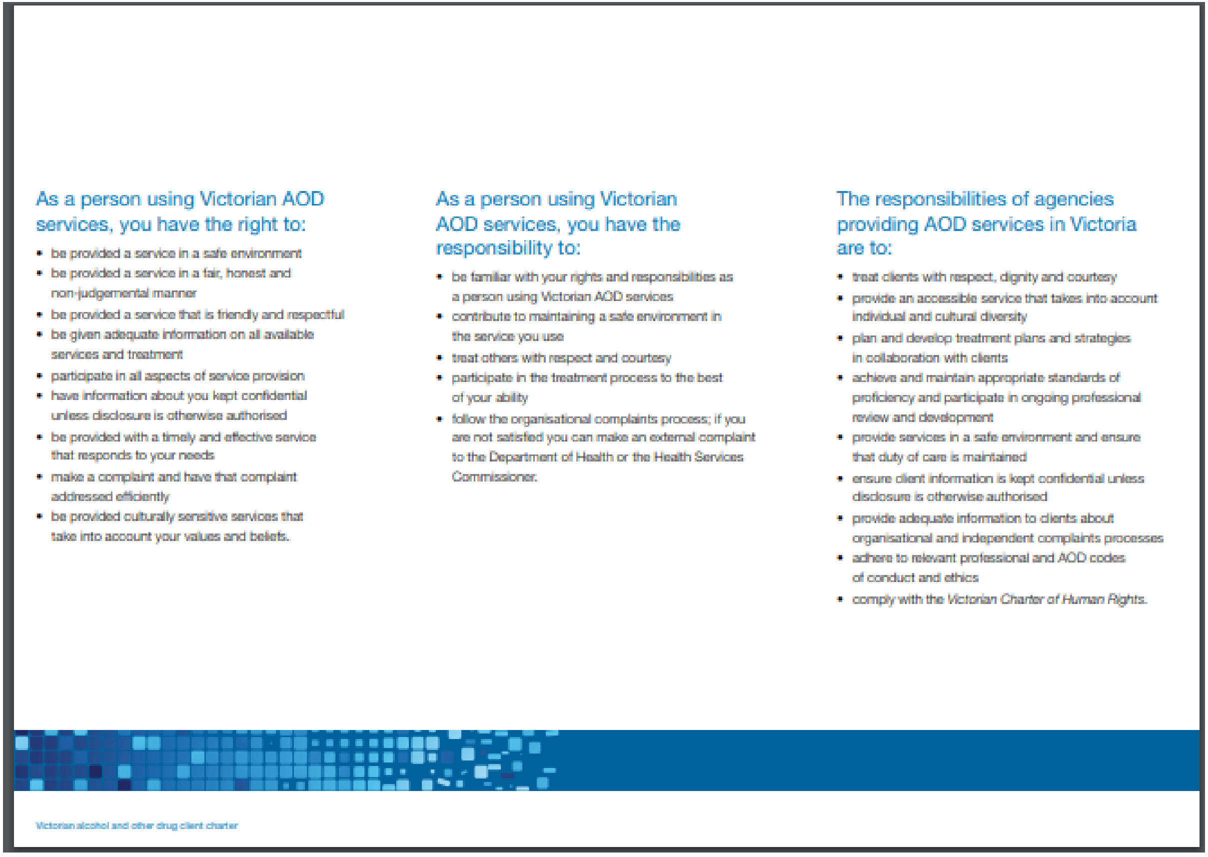
Victoria



As a person using Victorian AOD services, you have the right to:

- be provided a service in a safe environment
- be provided a service in a fair, honest and non-judgemental manner
- be provided a service that is friendly and respectful
- be given adequate information on all available services and treatment
- participate in all aspects of service provision
- have information about you kept confidential unless disclosure is otherwise authorised
- be provided with a timely and effective service that responds to your needs
- make a complaint and have that complaint addressed efficiently
- be provided culturally sensitive services that take into account your values and beliefs.

As a person using Victorian AOD services, you have the responsibility to:

- be familiar with your rights and responsibilities as a person using Victorian AOD services
- contribute to maintaining a safe environment in the service you use
- treat others with respect and courtesy
- participate in the treatment process to the best of your ability
- follow the organisational complaints process; if you are not satisfied you can make an external complaint to the Department of Health or the Health Services Commissioner.

The responsibilities of agencies providing AOD services in Victoria are to:

- treat clients with respect, dignity and courtesy
- provide an accessible service that takes into account individual and cultural diversity
- plan and develop treatment plans and strategies in collaboration with clients
- achieve and maintain appropriate standards of proficiency and participate in ongoing professional review and development
- provide services in a safe environment and ensure that duty of care is maintained
- ensure client information is kept confidential unless disclosure is otherwise authorised
- provide adequate information to clients about organisational and independent complaints processes
- adhere to relevant professional and AOD codes of conduct and ethics
- comply with the *Victorian Charter of Human Rights*.

Victorian alcohol and other drug client charter

Appendix 3: Information for SHARC consumers brochure

Your Privacy

Information about consumers obtained by SHARC staff in the course of providing a service is private and confidential. The Privacy and Data Protection Act 2014 outlines consumer rights in regard to privacy and confidentiality as they relate to the state of Victoria. SHARC supports, complies with and where possible strives to exceed the requirements of this Act.

SHARC will:

- Keep your personal information confidential
- Not disclose your personal information unless otherwise authorised
- Provide you lawful access to your personal information upon request

We are an inclusive service, everyone is welcome!

About us

Self Help Addiction Resource Centre (SHARC) promotes self-help approaches to recovery from alcohol and drug related issues. A unique, peer-led organisation, SHARC is a pioneer in the areas of self-help, peer support, consumer advocacy and promoting the value of lived experience.

Our vision

We envision a world where all people affected by the impact of addiction can proudly and openly seek help, help each other and demonstrate the living proof that recovery is possible.

Our mission

To provide opportunities for individuals, families and communities affected by addiction and related problems to recover and achieve meaningful, satisfying and contributing lives. To provide models of practice for family support, consumer participation and peer based recovery support; and influence practice in the field of addiction and other related health domains.

Our programs and services include:

- Association of Participating Service Users (APSU)
- Family Drug Help (FDH)
- Residential Peer Programs
- Peer Support Projects

Contact us:
Self Help Addiction Resource Centre
140 Grange Road, Carnegie Vic 3163
PH: 03 9573 1700 Fax: 03 9572 3498
Email: info@sharc.org.au
www.sharc.org.au

sharc

Self Help Addiction Resource Centre

Information for SHARC consumers

A consumer is someone who has accessed SHARC's programs and services. They may be individuals, family members or friends who are impacted by drug and alcohol use.

Your Rights & Responsibilities

SHARC upholds the rights and responsibilities listed in the Department of Health's Victorian Alcohol and Other Drug Client Charter.

As a SHARC consumer you have the right to:

- a service that is respectful and non-judgemental
- refuse SHARC services
- be provided care in a safe, drug free environment
- know the identity and qualifications of staff providing your care
- privacy
- lawful access to your file
- have information about you kept confidential unless disclosure is authorised
- make a complaint and have that complaint addressed efficiently.

As a SHARC consumer your responsibilities are to:

- accept the consequences of your own informed decisions
- respect the privacy and confidentiality of other SHARC consumers
- notify staff of any concerns you have about SHARC's programs and service
- behave in a way that is respectful and contributes to maintaining a safe environment at SHARC
- provide complete and accurate information where appropriate to help us help you.

Your Feedback

SHARC welcomes your feedback, whether it is a compliment or a complaint, as it assists us in improving our programs and services.

If you have a complaint about your experience of SHARC, we welcome you to provide your complaint, written or verbal, to the CEO or the relevant manager. SHARC's complaints policy aims to ensure that:

- complaints are taken seriously and investigated in a timely manner
- complaints are resolved through a fair process, without fear of reprisal
- complaints are handled in a confidential manner
- your feedback, where possible, is used to improve our services to benefit all consumers.

If you're not satisfied with the action taken by SHARC about the complaint, it can be referred to the Health Services Commissioner.

How can I give feedback about SHARC?

- Speak to a member of our staff
- Give us your feedback online at www.sharc.org.au/complimentscomplaints
- Fill out our feedback form and place it in the Feedback Box at SHARC reception
- Give us a call on 9573 1700 or email info@sharc.org.au

Feedback can be provided anonymously

Consumer Participation

Consumer participation at SHARC means we include consumers in decisions affecting their own treatment; and involve them in the planning, development and evaluation of SHARCs programs and services.

How can I get involved?

Become a member of SHARC for $5 per year

As a member, you can support the work we do and engage with the SHARC community. You will receive updates on our work, copies of our newsletters, invitations to SHARC events (including our AGM), and have voting rights to elect the SHARC Board of Governance.

Become a member of APSU for free

The Association of Participating Service Users (APSU) is a Victorian consumer representative body and a service of SHARC. APSU believes that people who use drug and alcohol services have a wealth of knowledge and experience. APSU has been set up to ensure that consumers' opinions, ideas and experiences contribute to policy, research, service provision and professional development.

Become a member at
www.sharc.org.au
or ask one of our staff for a membership form.

Appendix 4: SHARC feedback brochure

Feedback

How can I give feedback about SHARC?

- Speak to a member of our staff
- Give us your feedback online at www.sharc.org.au/complimentscomplaints
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Email: info@sharc.org.au
www.sharc.org.au

sharc

Self Help Addiction Resource Centre

Feedback

SHARC welcomes your feedback, whether it is a compliment or a complaint, as it assists us in improving our services.

The Process

What happens with my feedback?

Verbal feedback will be acknowledged and responded to by staff and written feedback will be directed to the CEO or the relevant manager.

If it is a written complaint:

- you will receive acknowledgement of your feedback within a week
- the complaint will be investigated and you will be provided with the time frame for our response
- all parties involved will be consulted
- where possible, complaints will be investigated and resolved within three weeks of receipt
- once the investigation is completed, you will recieve a formal response from us

If you're not satisfied with the outcome we will:

- Support you to speak to the Chairperson of the Board of Governance and/or the funding body relevant to their area of complaint
- Support you to seek further assistance from the Office of the Health Service Commissioner or other appropriate agency

Office of the Health Services Commissioner
An independent body established to receive and resolve complaints about healthcare.
Telephone: 1300 582 113.
TTY: 1800 136 066 (toll free)
www.health.vic.gov.au/hsc

Feedback, Compliments & Complaints

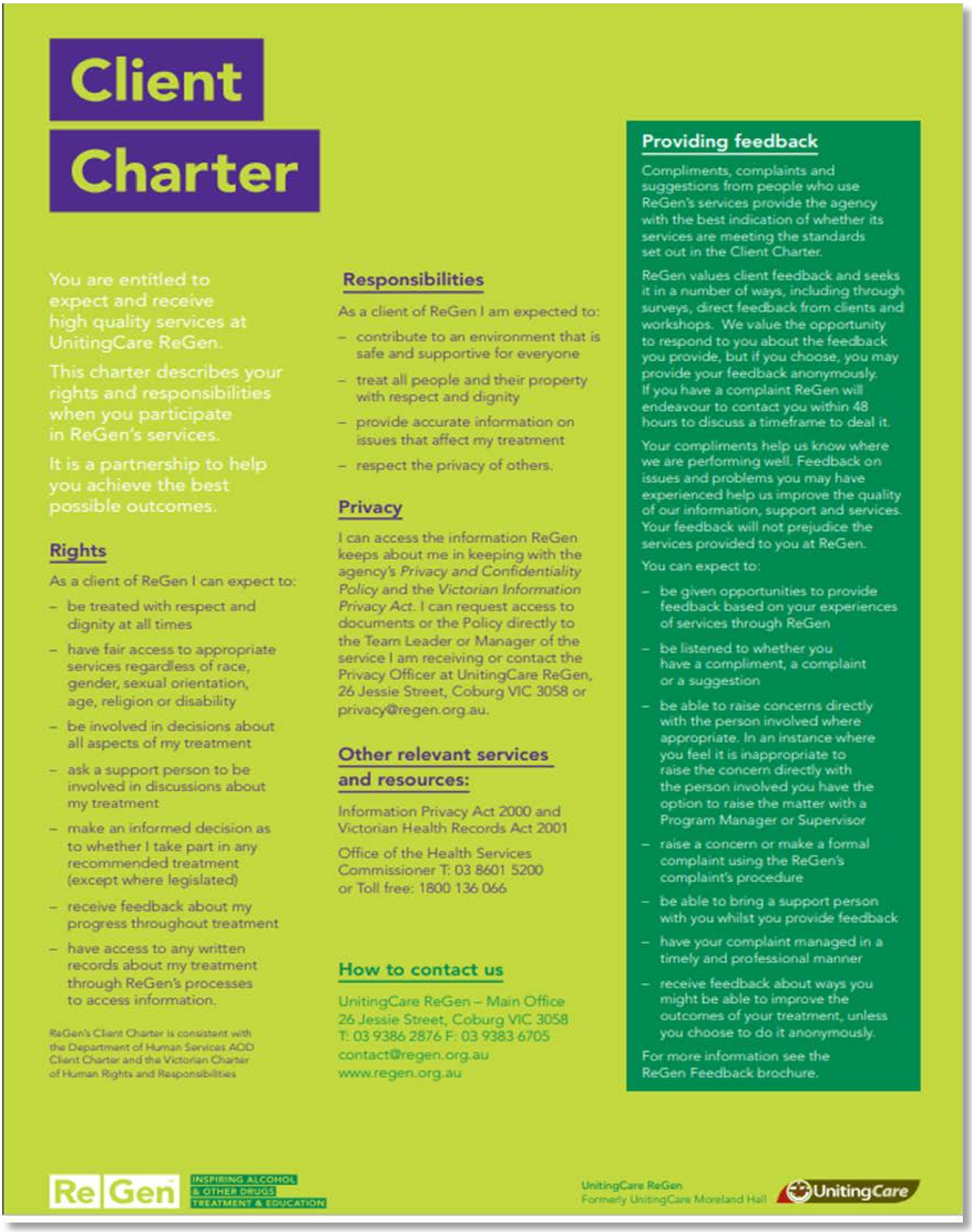
Name:
(optional)

Contact:
(optional)
Do you require an interpreter? Y/N

Please tick:
Feedback ☐
Compliment ☐
Complaint ☐

Your Feedback

Appendix 5: Uniting Regen Client Charter



Client Charter

You are entitled to expect and receive high quality services at UnitingCare ReGen.

This charter describes your rights and responsibilities when you participate in ReGen's services.

It is a partnership to help you achieve the best possible outcomes.

Rights

As a client of ReGen I can expect to:

- be treated with respect and dignity at all times
- have fair access to appropriate services regardless of race, gender, sexual orientation, age, religion or disability
- be involved in decisions about all aspects of my treatment
- ask a support person to be involved in discussions about my treatment
- make an informed decision as to whether I take part in any recommended treatment (except where legislated)
- receive feedback about my progress throughout treatment
- have access to any written records about my treatment through ReGen's processes to access information.

ReGen's Client Charter is consistent with the Department of Human Services AOD Client Charter and the Victorian Charter of Human Rights and Responsibilities

Responsibilities

As a client of ReGen I am expected to:

- contribute to an environment that is safe and supportive for everyone
- treat all people and their property with respect and dignity
- provide accurate information on issues that affect my treatment
- respect the privacy of others.

Privacy

I can access the information ReGen keeps about me in keeping with the agency's *Privacy and Confidentiality Policy* and the *Victorian Information Privacy Act*. I can request access to documents or the Policy directly to the Team Leader or Manager of the service I am receiving or contact the Privacy Officer at UnitingCare ReGen, 26 Jessie Street, Coburg VIC 3058 or privacy@regen.org.au.

Other relevant services and resources:

Information Privacy Act 2000 and Victorian Health Records Act 2001

Office of the Health Services Commissioner T: 03 8601 5200 or Toll free: 1800 136 066

How to contact us

UnitingCare ReGen – Main Office
26 Jessie Street, Coburg VIC 3058
T: 03 9386 2876 F: 03 9383 6705
contact@regen.org.au
www.regen.org.au

Providing feedback

Compliments, complaints and suggestions from people who use ReGen's services provide the agency with the best indication of whether its services are meeting the standards set out in the Client Charter.

ReGen values client feedback and seeks it in a number of ways, including through surveys, direct feedback from clients and workshops. We value the opportunity to respond to you about the feedback you provide, but if you choose, you may provide your feedback anonymously. If you have a complaint ReGen will endeavour to contact you within 48 hours to discuss a timeframe to deal it.

Your compliments help us know where we are performing well. Feedback on issues and problems you may have experienced help us improve the quality of our information, support and services. Your feedback will not prejudice the services provided to you at ReGen.

You can expect to:

- be given opportunities to provide feedback based on your experiences of services through ReGen
- be listened to whether you have a compliment, a complaint or a suggestion
- be able to raise concerns directly with the person involved where appropriate. In an instance where you feel it is inappropriate to raise the concern directly with the person involved you have the option to raise the matter with a Program Manager or Supervisor
- raise a concern or make a formal complaint using the ReGen's complaint's procedure
- be able to bring a support person with you whilst you provide feedback
- have your complaint managed in a timely and professional manner
- receive feedback about ways you might be able to improve the outcomes of your treatment, unless you choose to do it anonymously.

For more information see the ReGen Feedback brochure.

ReGen
INSPIRING ALCOHOL & OTHER DRUGS TREATMENT & EDUCATION

UnitingCare ReGen
Formerly UnitingCare Moreland Hall

UnitingCare

Appendix 6: Uniting Regen complaints process pamphlet

Getting access to your information

Access to your information

You can request and gain access to or make corrections to your personal and health information held by ReGen.

Your right to access this information however, is subject to certain exceptions contained in the privacy legislation.

For example, if the information relates to another person or existing or anticipated legal proceedings, you may not be able to view it.

If you want to see your personal or health information, ask for a copy of our **Client Privacy and Confidentiality Policy** from a staff member.

To make a formal request, or a complaint concerning the handling of your personal or health information, contact our privacy officer in writing:

The Privacy Officer
UnitingCare ReGen
26 Jessie St
Coburg VIC 3058
T: 03 9386 2876
privacy@regen.org.au

If your request for access or correction to personal or health information is declined, the privacy officer will explain the reasons for this, in writing, within 30 days.

If you are dissatisfied with the privacy officer's response, you can contact:

The Office of the Victorian Privacy Commissioner
Privacy Victoria
Level 11, 10-16 Queen St
Melbourne VIC 3000
Local rate: 1300 666 444
enquiries@privacy.vic.gov.au

Complaints Organisations

Health Services Commissioner
Office of the Health Services Commissioner
Complaints & Information
30th Floor, 570 Bourke St
Melbourne VIC 3000
T: 03 8601 5200
Toll free: 1800 136 006

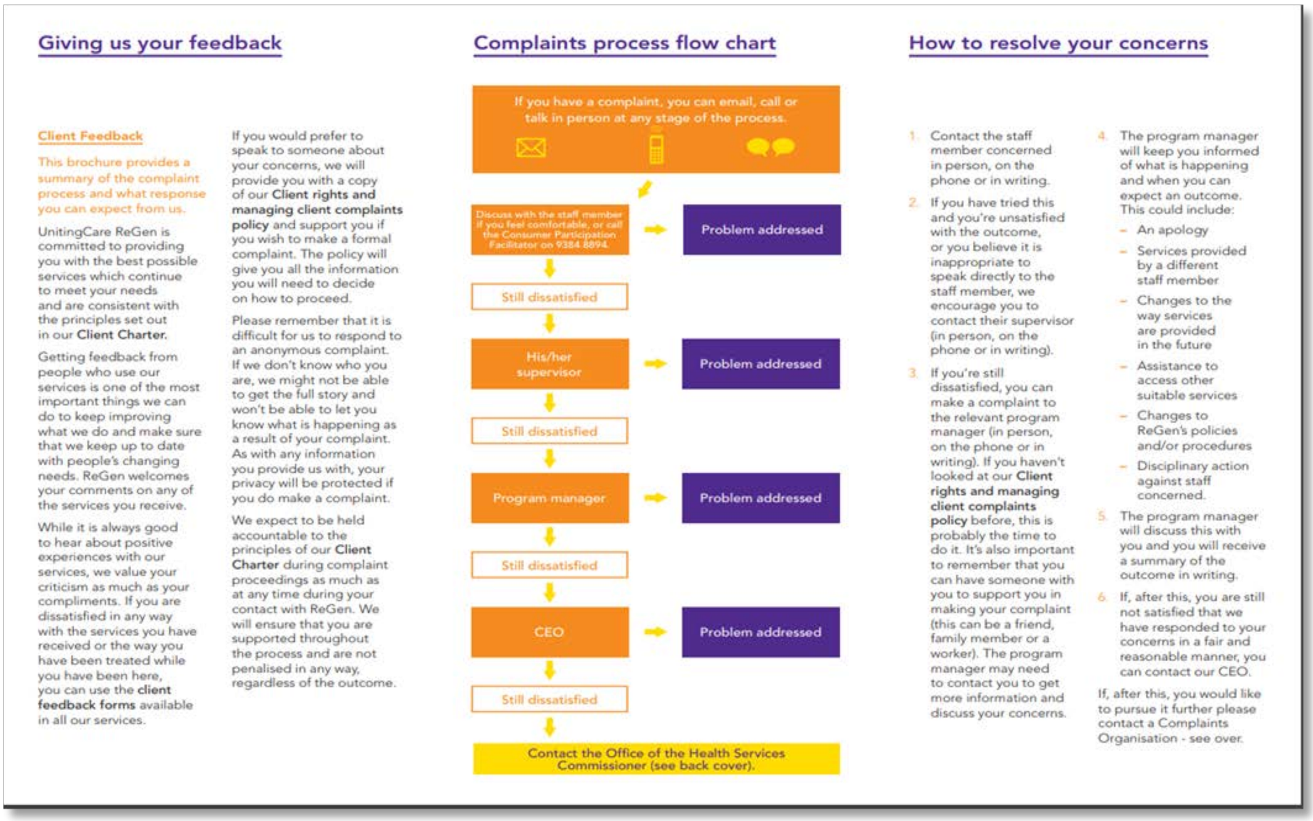
Equal Opportunity and Human Rights Commission
Level 3, 204 Lygon St
Carlton VIC 3053
Local rate: 1300 891 848
information@veohrc.vic.gov.au

Contact us

UnitingCare ReGen
Formerly UnitingCare Moreland Hall

26 Jessie Street
Coburg VIC 3058
T 03 9386 2876
F 03 9383 6705
contact@regen.org.au
www.regen.org.au

Providing feedback & making complaints



Giving us your feedback

Client Feedback

This brochure provides a summary of the complaint process and what response you can expect from us.

UnitingCare ReGen is committed to providing you with the best possible services which continue to meet your needs and are consistent with the principles set out in our **Client Charter.**

Getting feedback from people who use our services is one of the most important things we can do to keep improving what we do and make sure that we keep up to date with people's changing needs. ReGen welcomes your comments on any of the services you receive.

While it is always good to hear about positive experiences with our services, we value your criticism as much as your compliments. If you are dissatisfied in any way with the services you have received or the way you have been treated while you have been here, you can use the **client feedback forms** available in all our services.

If you would prefer to speak to someone about your concerns, we will provide you with a copy of our **Client rights and managing client complaints policy** and support you if you wish to make a formal complaint. The policy will give you all the information you will need to decide on how to proceed.

Please remember that it is difficult for us to respond to an anonymous complaint. If we don't know who you are, we might not be able to get the full story and won't be able to let you know what is happening as a result of your complaint. As with any information you provide us with, your privacy will be protected if you do make a complaint.

We expect to be held accountable to the principles of our **Client Charter** during complaint proceedings as much as at any time during your contact with ReGen. We will ensure that you are supported throughout the process and are not penalised in any way, regardless of the outcome.

Complaints process flow chart

If you have a complaint, you can email, call or talk in person at any stage of the process.

Discuss with the staff member if you feel comfortable, or call the Consumer Participation Facilitator on 9384 8894. → Problem addressed

Still dissatisfied

His/her supervisor → Problem addressed

Still dissatisfied

Program manager → Problem addressed

Still dissatisfied

CEO → Problem addressed

Still dissatisfied

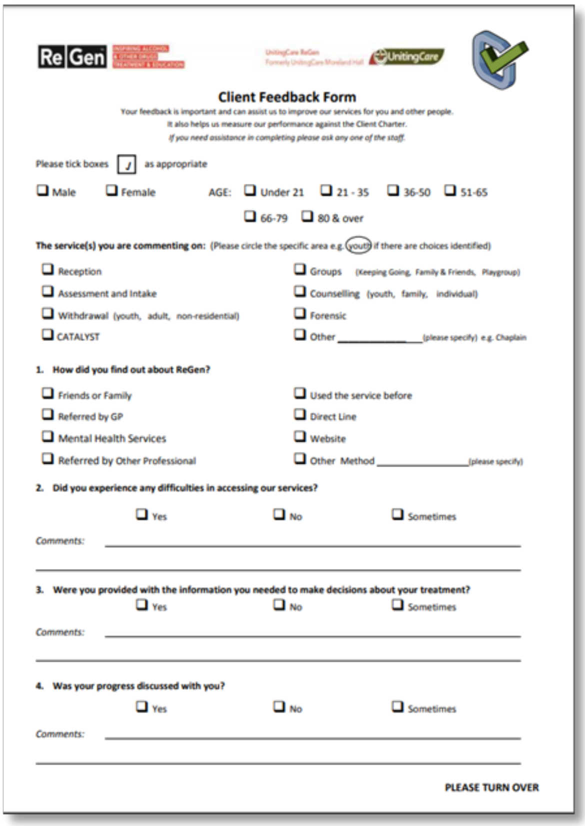
Contact the Office of the Health Services Commissioner (see back cover).

How to resolve your concerns

1. Contact the staff member concerned in person, on the phone or in writing.
2. If you have tried this and you're unsatisfied with the outcome, or you believe it is inappropriate to speak directly to the staff member, we encourage you to contact their supervisor (in person, on the phone or in writing).
3. If you're still dissatisfied, you can make a complaint to the relevant program manager (in person, on the phone or in writing). If you haven't looked at our **Client rights and managing client complaints policy** before, this is probably the time to do it. It's also important to remember that you can have someone with you to support you in making your complaint (this can be a friend, family member or a worker). The program manager may need to contact you to get more information and discuss your concerns.
4. The program manager will keep you informed of what is happening and when you can expect an outcome. This could include:
   - An apology
   - Services provided by a different staff member
   - Changes to the way services are provided in the future
   - Assistance to access other suitable services
   - Changes to ReGen's policies and/or procedures
   - Disciplinary action against staff concerned.
5. The program manager will discuss this with you and you will receive a summary of the outcome in writing.
6. If, after this, you are still not satisfied that we have responded to your concerns in a fair and reasonable manner, you can contact our CEO.

If, after this, you would like to pursue it further please contact a Complaints Organisation - see over.

Appendix 7: Uniting Regen client feedback form



Re Gen INSPIRING ALCOHOL & OTHER DRUGS TREATMENT & EDUCATION

UnitingCare ReGen
Formerly UnitingCare Moreland Hall
UnitingCare

Client Feedback Form

Your feedback is important and can assist us to improve our services for you and other people.
It also helps us measure our performance against the Client Charter.
If you need assistance in completing please ask any one of the staff.

Please tick boxes ☑ as appropriate

☐ Male ☐ Female AGE: ☐ Under 21 ☐ 21 - 35 ☐ 36-50 ☐ 51-65
☐ 66-79 ☐ 80 & over

The service(s) you are commenting on: (Please circle the specific area e.g. youth if there are choices identified)

☐ Reception	☐ Groups (Keeping Going, Family & Friends, Playgroup)
☐ Assessment and Intake	☐ Counselling (youth, family, individual)
☐ Withdrawal (youth, adult, non-residential)	☐ Forensic
☐ CATALYST	☐ Other ________________(please specify) e.g. Chaplain

1. How did you find out about ReGen?

☐ Friends or Family	☐ Used the service before
☐ Referred by GP	☐ Direct Line
☐ Mental Health Services	☐ Website
☐ Referred by Other Professional	☐ Other Method ________________(please specify)

2. Did you experience any difficulties in accessing our services?

☐ Yes ☐ No ☐ Sometimes

Comments: ________________________________

3. Were you provided with the information you needed to make decisions about your treatment?

☐ Yes ☐ No ☐ Sometimes

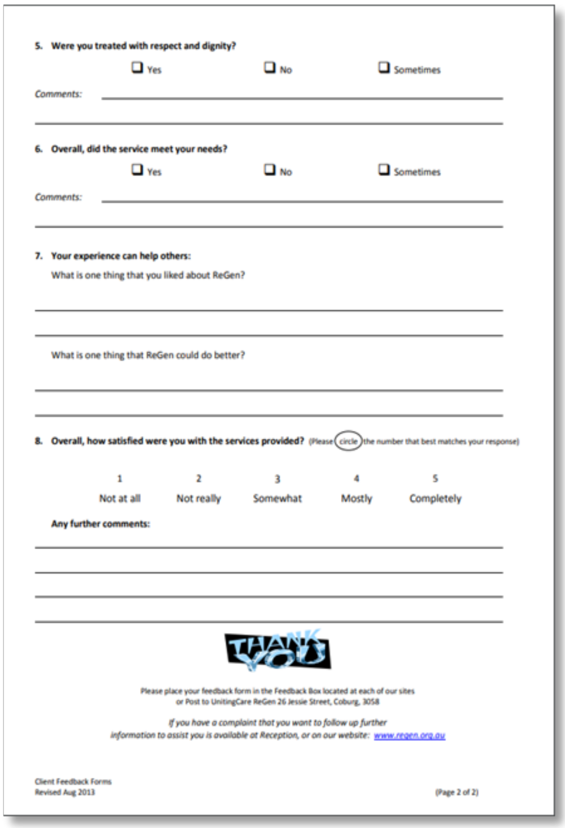
Comments: ________________________________

4. Was your progress discussed with you?

☐ Yes ☐ No ☐ Sometimes

Comments: ________________________________

PLEASE TURN OVER



5. Were you treated with respect and dignity?

☐ Yes ☐ No ☐ Sometimes

Comments: ________________________________

6. Overall, did the service meet your needs?

☐ Yes ☐ No ☐ Sometimes

Comments: ________________________________

7. Your experience can help others:

What is one thing that you liked about ReGen?

____

What is one thing that ReGen could do better?

____

8. Overall, how satisfied were you with the services provided? (Please circle the number that best matches your response)

1	2	3	4	5
Not at all	Not really	Somewhat	Mostly	Completely

Any further comments:

____

THANK YOU

Please place your feedback form in the Feedback Box located at each of our sites
or Post to UnitingCare ReGen 26 Jessie Street, Coburg, 3058

If you have a complaint that you want to follow up further
information to assist you is available at Reception, or on our website: www.regen.org.au

Client Feedback Forms
Revised Aug 2013

(Page 2 of 2)

Appendix 8: Promotional materials for Regional Roadshow

VMIAC & APSU ROADSHOW

27TH APRIL
1:00-3:30PM

BENDIGO
VENUE TO BE CONFIRMED
Light Afternoon Tea Provided

In order to help VMIAC and APSU understand how we can best engage with all parts of Victoria, we invite mental health consumers and/or users of drug and alcohol services to join us to explore the issues affecting the mental health and AOD systems in their area.

VMIAC
by and for consumers

APSU
Association of Participating Service Users
APSU is a service of sharc

FOR MORE INFO OR TO RSVP
erafferty@sharc.org.au
(03) 9573 1778

Do you live in Gippsland?
Have you used alcohol and drug or mental health services?
We'd love to hear from you!
We are coming to Traralgon on 29 June.
Join us for afternoon tea and a chat!

Association of Participating Service Users (APSU)
Victorian Mental Illness Awareness Council (VMIAC)

Appendix 9: CAC recruiting flyer

We're Now Recruiting for our New
Alcohol and Other Drug (AOD)
Community Advisory Committee (CAC)

The SHARC / Windana partnership is looking for TEN people who have used AOD services to join our new Community Advisory Committee.

If you are a consumer, carer or family member who has been impacted by alcohol and other drugs and you want to use your expertise to make changes and improve these services, we invite you to express interest.

Preference will be given to those people with experience at SHARC and/or Windana.

You will be paid $50 per meeting for your time.

This is your chance to have a say and make a difference in the AOD sector!

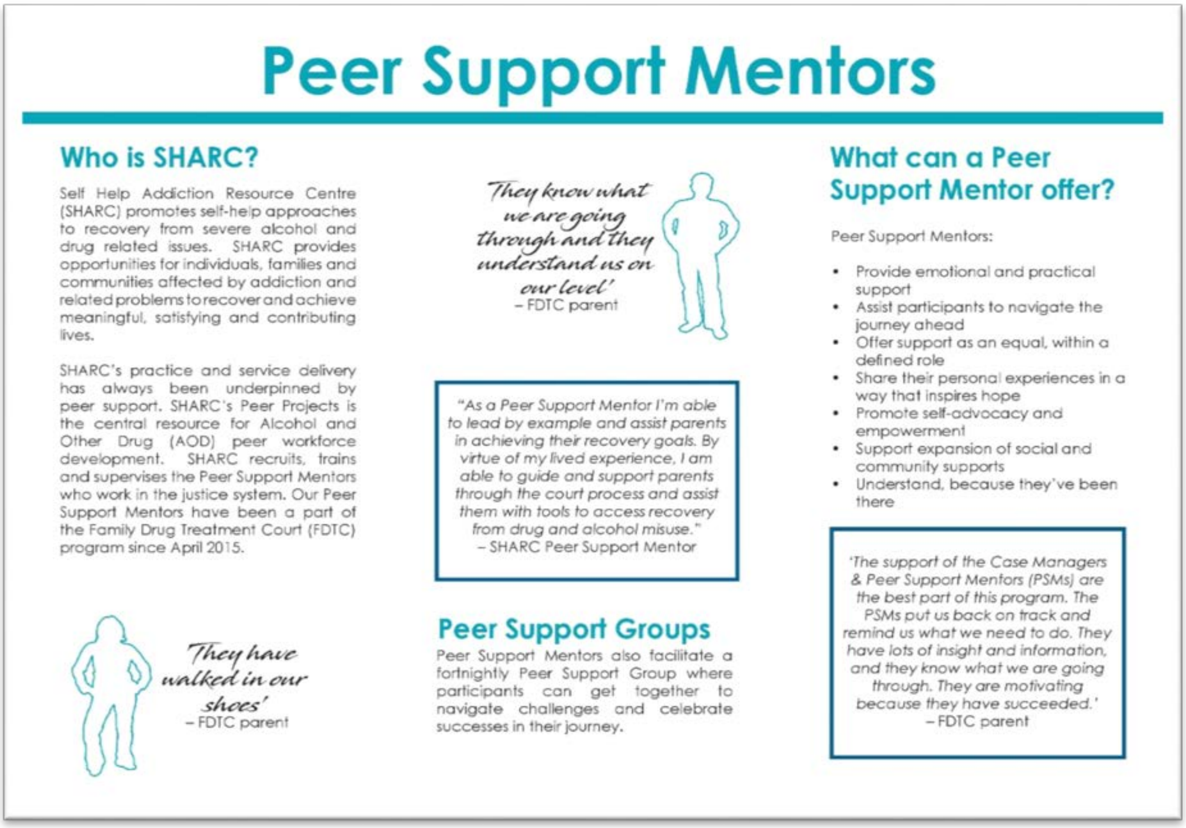
Send your expression of interest today to Natalie Wloch via email: nwloch@sharc.org.au

Applications close on Friday 1st April 2016.

sharc
Self Help Addiction Resource Centre

windana
Drug & Alcohol Recovery

Appendix 10: Peer Mentors in Justice brochure.



Peer Support Mentors

Who is SHARC?

Self Help Addiction Resource Centre (SHARC) promotes self-help approaches to recovery from severe alcohol and drug related issues. SHARC provides opportunities for individuals, families and communities affected by addiction and related problems to recover and achieve meaningful, satisfying and contributing lives.

SHARC's practice and service delivery has always been underpinned by peer support. SHARC's Peer Projects is the central resource for Alcohol and Other Drug (AOD) peer workforce development. SHARC recruits, trains and supervises the Peer Support Mentors who work in the justice system. Our Peer Support Mentors have been a part of the Family Drug Treatment Court (FDTC) program since April 2015.

'They have walked in our shoes'
– FDTC parent

'They know what we are going through and they understand us on our level'
– FDTC parent

> *"As a Peer Support Mentor I'm able to lead by example and assist parents in achieving their recovery goals. By virtue of my lived experience, I am able to guide and support parents through the court process and assist them with tools to access recovery from drug and alcohol misuse."*
> – SHARC Peer Support Mentor

Peer Support Groups

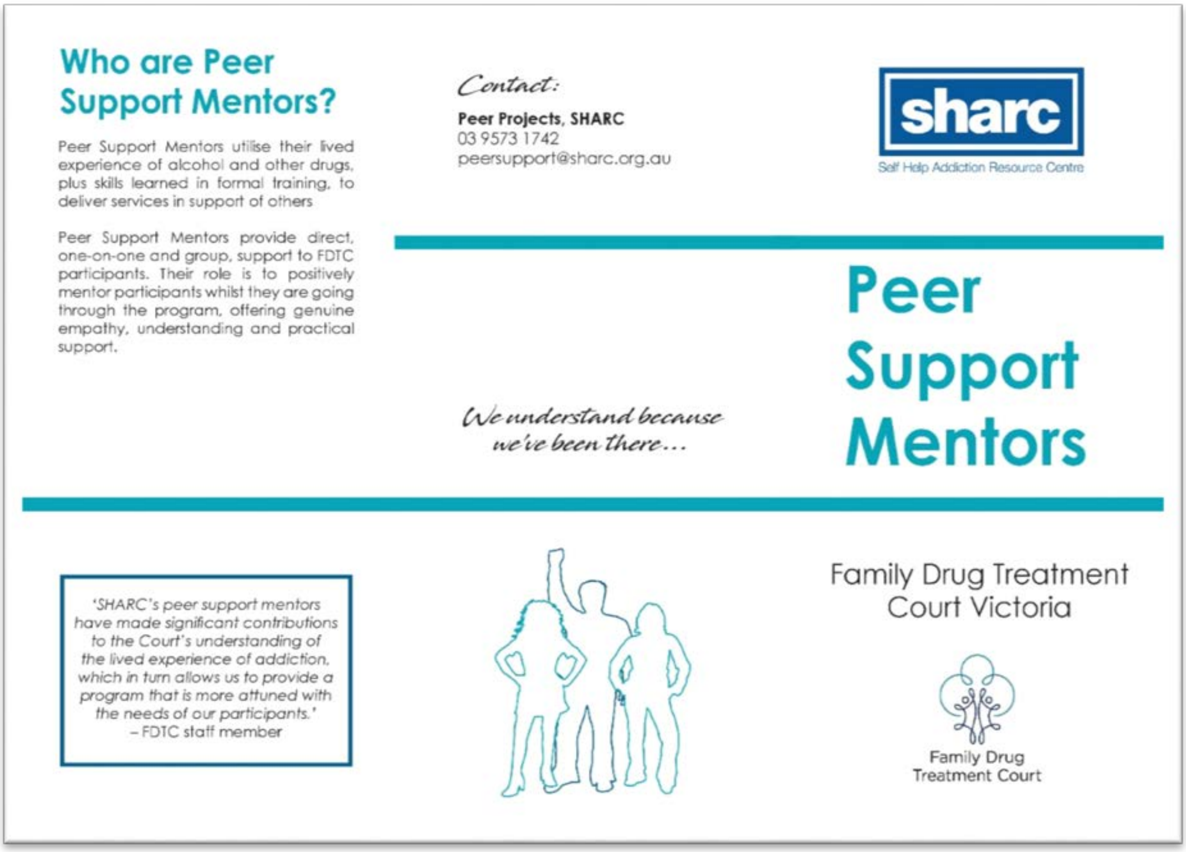
Peer Support Mentors also facilitate a fortnightly Peer Support Group where participants can get together to navigate challenges and celebrate successes in their journey.

What can a Peer Support Mentor offer?

Peer Support Mentors:

- Provide emotional and practical support
- Assist participants to navigate the journey ahead
- Offer support as an equal, within a defined role
- Share their personal experiences in a way that inspires hope
- Promote self-advocacy and empowerment
- Support expansion of social and community supports
- Understand, because they've been there

> *'The support of the Case Managers & Peer Support Mentors (PSMs) are the best part of this program. The PSMs put us back on track and remind us what we need to do. They have lots of insight and information, and they know what we are going through. They are motivating because they have succeeded.'*
> – FDTC parent



Who are Peer Support Mentors?

Peer Support Mentors utilise their lived experience of alcohol and other drugs, plus skills learned in formal training, to deliver services in support of others

Peer Support Mentors provide direct, one-on-one and group, support to FDTC participants. Their role is to positively mentor participants whilst they are going through the program, offering genuine empathy, understanding and practical support.

> *'SHARC's peer support mentors have made significant contributions to the Court's understanding of the lived experience of addiction, which in turn allows us to provide a program that is more attuned with the needs of our participants.'*
> – FDTC staff member

Contact:

Peer Projects, SHARC
03 9573 1742
peersupport@sharc.org.au

sharc
Self Help Addiction Resource Centre

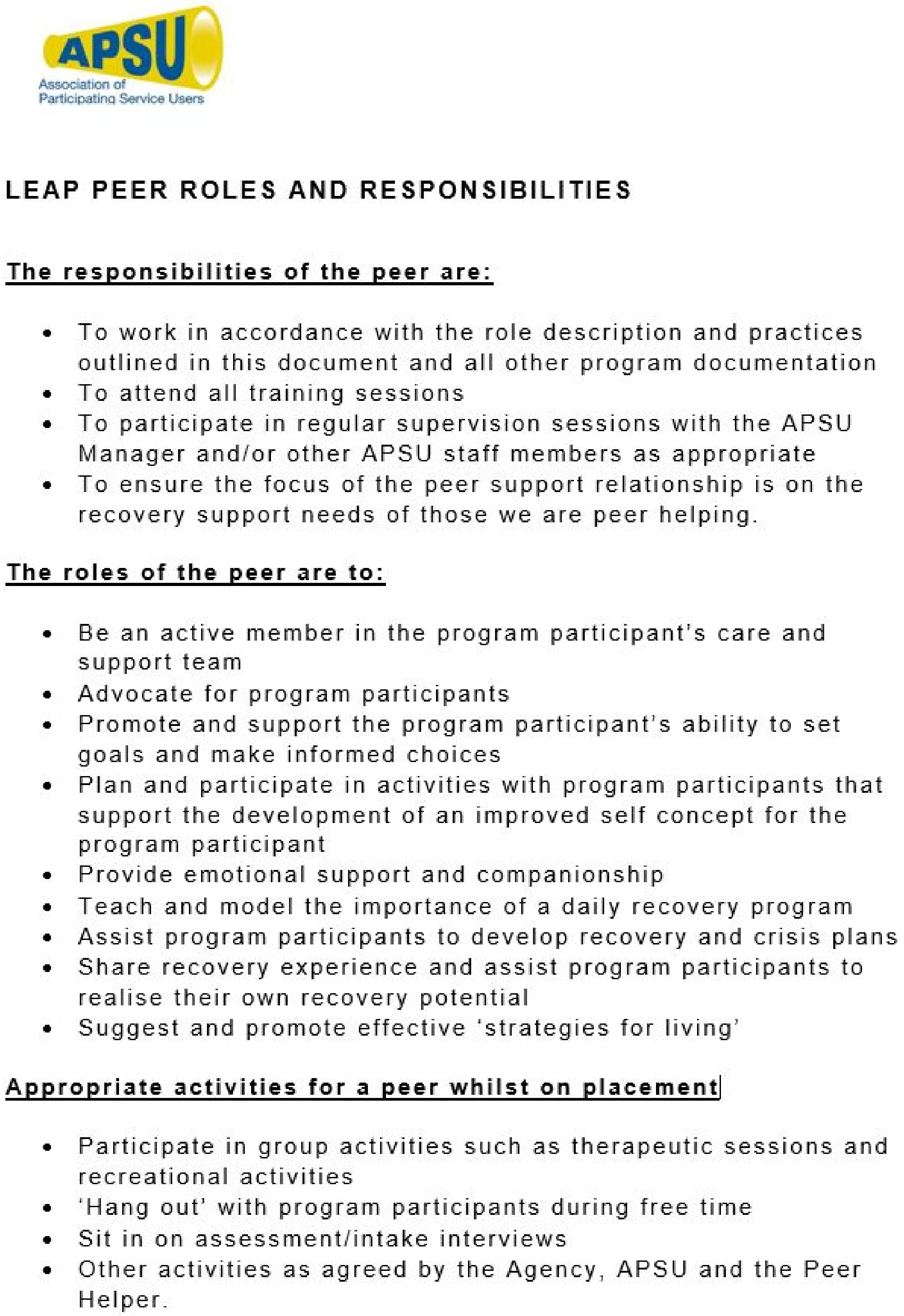
Peer Support Mentors

We understand because we've been there…

Family Drug Treatment Court Victoria

Family Drug Treatment Court

Appendix 11: Lived Experience Applied (LEAP) peer roles and responsibilities



Association of Participating Service Users

LEAP PEER ROLES AND RESPONSIBILITIES

The responsibilities of the peer are:

- To work in accordance with the role description and practices outlined in this document and all other program documentation
- To attend all training sessions
- To participate in regular supervision sessions with the APSU Manager and/or other APSU staff members as appropriate
- To ensure the focus of the peer support relationship is on the recovery support needs of those we are peer helping.

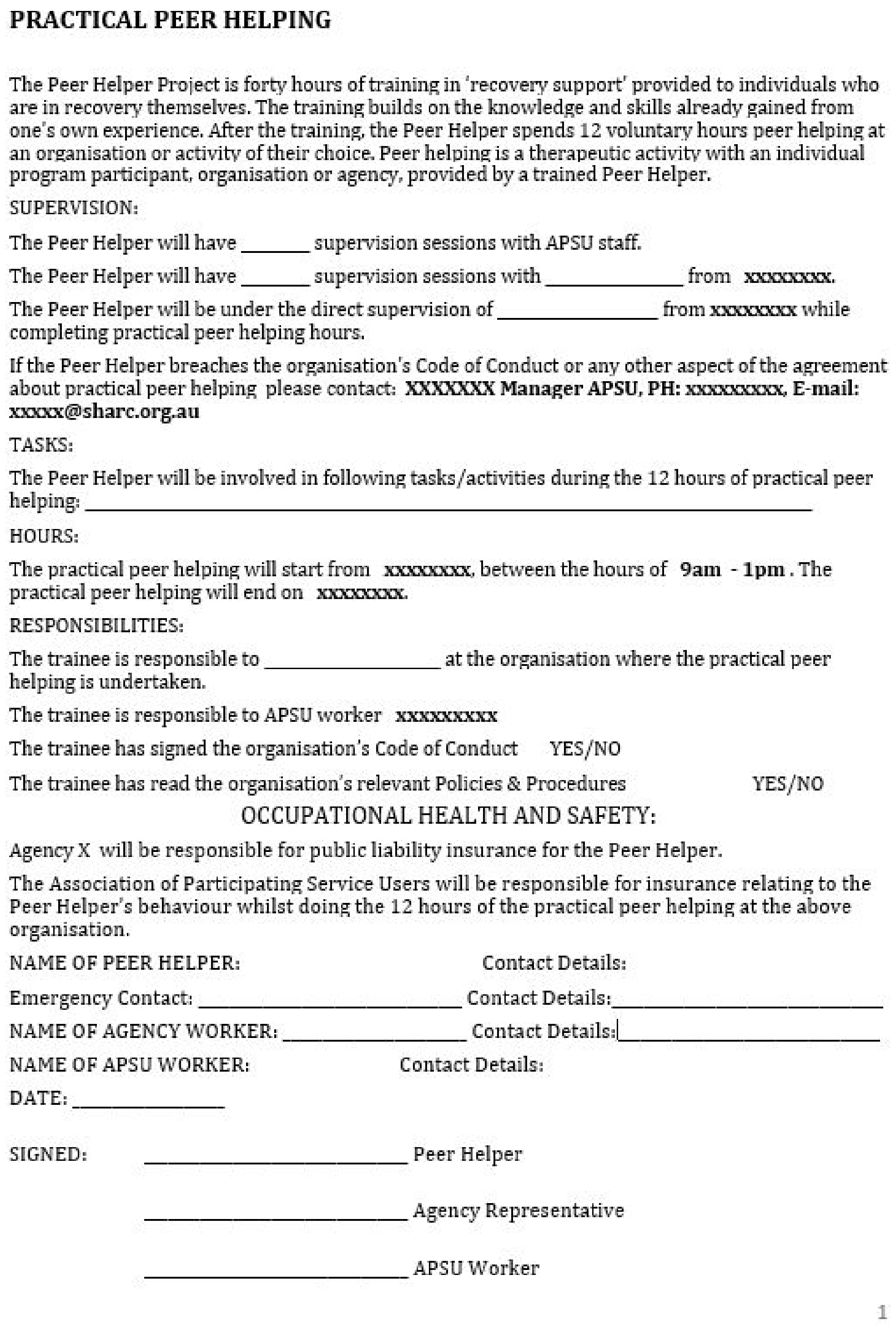
The roles of the peer are to:

- Be an active member in the program participant's care and support team
- Advocate for program participants
- Promote and support the program participant's ability to set goals and make informed choices
- Plan and participate in activities with program participants that support the development of an improved self concept for the program participant
- Provide emotional support and companionship
- Teach and model the importance of a daily recovery program
- Assist program participants to develop recovery and crisis plans
- Share recovery experience and assist program participants to realise their own recovery potential
- Suggest and promote effective 'strategies for living'

Appropriate activities for a peer whilst on placement

- Participate in group activities such as therapeutic sessions and recreational activities
- 'Hang out' with program participants during free time
- Sit in on assessment/intake interviews
- Other activities as agreed by the Agency, APSU and the Peer Helper.

Appendix 12: LEAP Peer Training placement agreement



PRACTICAL PEER HELPING

The Peer Helper Project is forty hours of training in 'recovery support' provided to individuals who are in recovery themselves. The training builds on the knowledge and skills already gained from one's own experience. After the training, the Peer Helper spends 12 voluntary hours peer helping at an organisation or activity of their choice. Peer helping is a therapeutic activity with an individual program participant, organisation or agency, provided by a trained Peer Helper.

SUPERVISION:

The Peer Helper will have _______ supervision sessions with APSU staff.

The Peer Helper will have _______ supervision sessions with ______________ from **xxxxxxxx.**

The Peer Helper will be under the direct supervision of ________________ from **xxxxxxxx** while completing practical peer helping hours.

If the Peer Helper breaches the organisation's Code of Conduct or any other aspect of the agreement about practical peer helping please contact: **XXXXXXX Manager APSU, PH: xxxxxxxxx, E-mail: xxxxx@sharc.org.au**

TASKS:

The Peer Helper will be involved in following tasks/activities during the 12 hours of practical peer helping: ____

HOURS:

The practical peer helping will start from **xxxxxxxx**, between the hours of **9am - 1pm** . The practical peer helping will end on **xxxxxxxx.**

RESPONSIBILITIES:

The trainee is responsible to _________________ at the organisation where the practical peer helping is undertaken.

The trainee is responsible to APSU worker **xxxxxxxxx**

The trainee has signed the organisation's Code of Conduct YES/NO

The trainee has read the organisation's relevant Policies & Procedures YES/NO

OCCUPATIONAL HEALTH AND SAFETY:

Agency X will be responsible for public liability insurance for the Peer Helper.

The Association of Participating Service Users will be responsible for insurance relating to the Peer Helper's behaviour whilst doing the 12 hours of the practical peer helping at the above organisation.

NAME OF PEER HELPER: Contact Details:

Emergency Contact: ___________________________ Contact Details:____________________________

NAME OF AGENCY WORKER: ___________________ Contact Details:___________________________

NAME OF APSU WORKER: Contact Details:

DATE: _______________

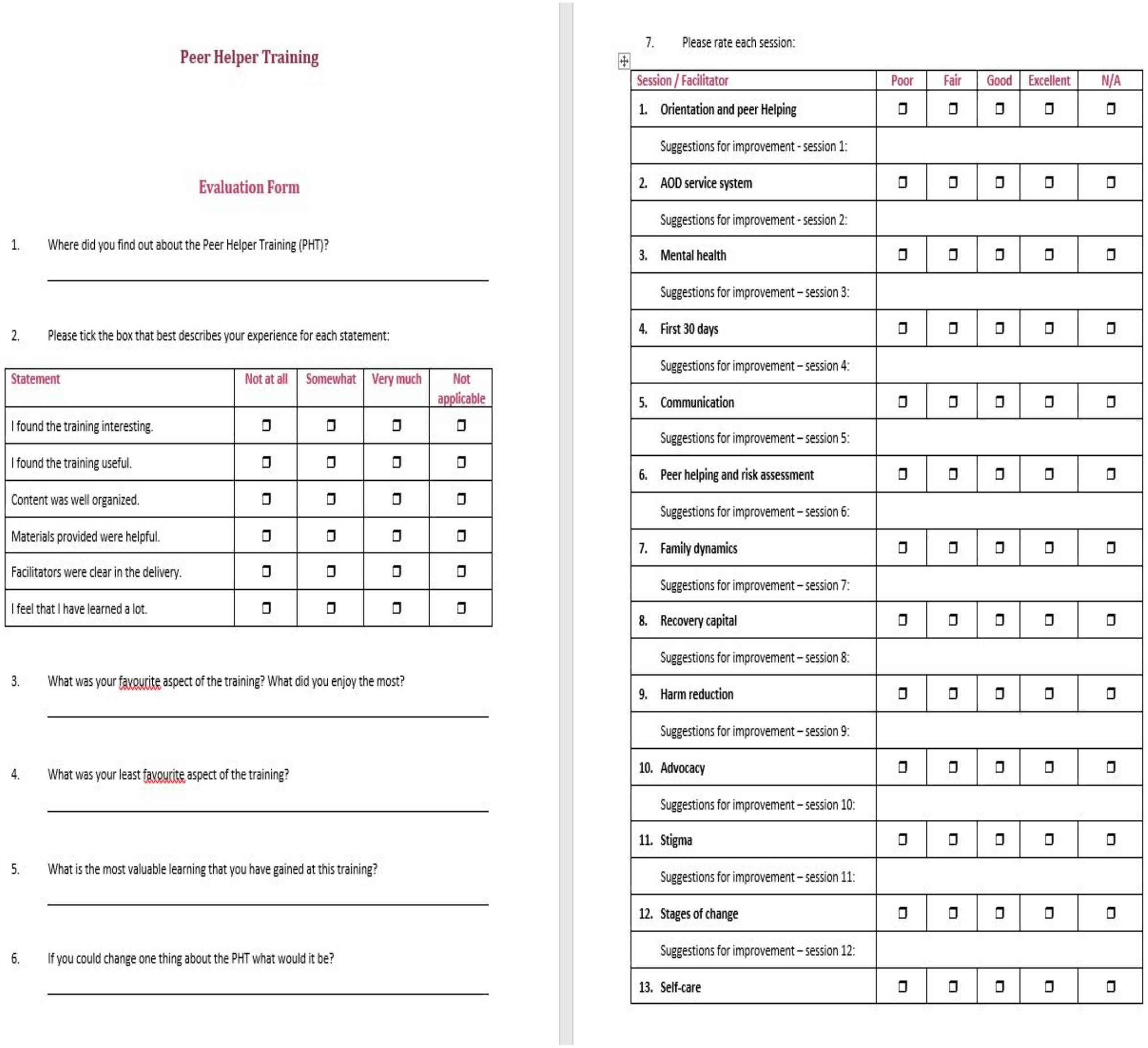
SIGNED: ___________________________ Peer Helper

___________________________ Agency Representative

___________________________ APSU Worker

1

Appendix 13: LEAP - Peer Training evaluation form



Peer Helper Training

Evaluation Form

1. Where did you find out about the Peer Helper Training (PHT)?

____

2. Please tick the box that best describes your experience for each statement:

Statement	Not at all	Somewhat	Very much	Not applicable
I found the training interesting.	☐	☐	☐	☐
I found the training useful.	☐	☐	☐	☐
Content was well organized.	☐	☐	☐	☐
Materials provided were helpful.	☐	☐	☐	☐
Facilitators were clear in the delivery.	☐	☐	☐	☐
I feel that I have learned a lot.	☐	☐	☐	☐

3. What was your favourite aspect of the training? What did you enjoy the most?

____

4. What was your least favourite aspect of the training?

____

5. What is the most valuable learning that you have gained at this training?

____

6. If you could change one thing about the PHT what would it be?

____

7. Please rate each session:

Session / Facilitator	Poor	Fair	Good	Excellent	N/A
1. Orientation and peer Helping	☐	☐	☐	☐	☐
Suggestions for improvement - session 1:					
2. AOD service system	☐	☐	☐	☐	☐
Suggestions for improvement - session 2:					
3. Mental health	☐	☐	☐	☐	☐
Suggestions for improvement – session 3:					
4. First 30 days	☐	☐	☐	☐	☐
Suggestions for improvement – session 4:					
5. Communication	☐	☐	☐	☐	☐
Suggestions for improvement – session 5:					
6. Peer helping and risk assessment	☐	☐	☐	☐	☐
Suggestions for improvement – session 6:					
7. Family dynamics	☐	☐	☐	☐	☐
Suggestions for improvement – session 7:					
8. Recovery capital	☐	☐	☐	☐	☐
Suggestions for improvement – session 8:					
9. Harm reduction	☐	☐	☐	☐	☐
Suggestions for improvement – session 9:					
10. Advocacy	☐	☐	☐	☐	☐
Suggestions for improvement – session 10:					
11. Stigma	☐	☐	☐	☐	☐
Suggestions for improvement – session 11:					
12. Stages of change	☐	☐	☐	☐	☐
Suggestions for improvement – session 12:					
13. Self-care	☐	☐	☐	☐	☐

Suggestions for improvement – session 13:	

8. Do you have any suggestions for future rounds of PHT?

____

9. Would you recommend PHT to other people in recovery (in the right circumstances)?
   a) yes
   b) no

10. How would you rate PHT overall from 1 to 10, where 1 is the lowest and 10 the highest mark?

____

11. Any final comments?

____

Thank you for your participation!

Appendix 14: CHP Consumer Participation Training Project

Consumer Participation Forum

When: Monday 27 October, 2014
Time: 10.00am to 3.00pm
Where: Fitzroy Town Hall

Guest Speaker

Jacques Boulet

'Houses, homes, relationship and participation: what will it take for us to get this right?'

You're invited to a forum for organisations, groups and individuals who are practicing consumer participation to:

- Learn about others who are practicing consumer participation and create networks
- Share ideas about best practice and innovations in consumer participation
- Challenge the way we think about consumer participation
- Develop recommendations for moving to higher level consumer participation

Lunch will be provided - please advise CHP of any dietary requirements.

RSVP: https://chpconsumerparticipationforum.eventbrite.com.au or ph: 8415 6210

Appendix 15:: CARE Consumer Participation Training Project

CARE

Consumer
Action
Responsive
Empowerment

Ideas Exchange
Thursday 4th May 2017

CONSUMER PARTICIPATION IN THE VICTORIAN ALCOHOL AND OTHER DRUGS (AOD) SECTOR

We invite service providers, consumers and policy makers from across the alcohol and drug, dual diagnosis and community health sectors to come together for our CARE Ideas Exchange.

When: Thursday 4 May 2017
9.00am – 4.00pm

Where: Ibis Hotel & Apartments
15-21 Therry Street, Melbourne

This opportunity will allow attendees to network with like-minded people, share ideas for innovation and explore options for ongoing collaboration.

Registration: https://apsu-and-taskforce.eventbrite.com.au

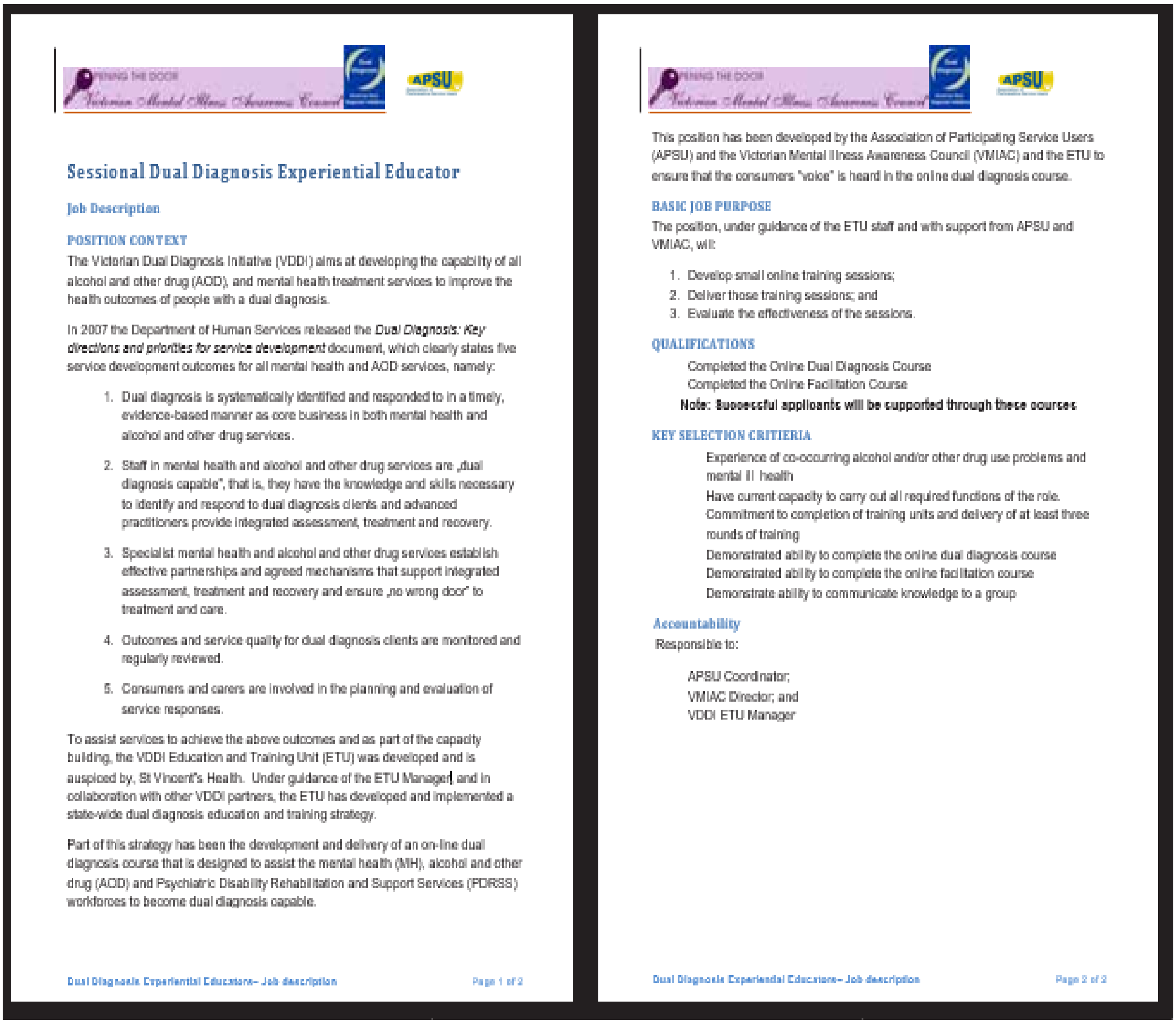
Enquiries: APSU – Natalie Wloch
Phone: (03) 9573 1742
Email: nwloch@sharc.org.au

APSU
Association of Participating Service Users
APSU is a service of sharc

TaskForce
Where hope finds help.

This event is funded by the Commonwealth Department of Health, Substance Misuse Service Delivery Grants Fund.

Appendix 16: Dual diagnosis experiential educator job description



Sessional Dual Diagnosis Experiential Educator

Job Description

POSITION CONTEXT

The Victorian Dual Diagnosis Initiative (VDDI) aims at developing the capability of all alcohol and other drug (AOD), and mental health treatment services to improve the health outcomes of people with a dual diagnosis.

In 2007 the Department of Human Services released the *Dual Diagnosis: Key directions and priorities for service development* document, which clearly states five service development outcomes for all mental health and AOD services, namely:

1. Dual diagnosis is systematically identified and responded to in a timely, evidence-based manner as core business in both mental health and alcohol and other drug services.
2. Staff in mental health and alcohol and other drug services are „dual diagnosis capable", that is, they have the knowledge and skills necessary to identify and respond to dual diagnosis clients and advanced practitioners provide integrated assessment, treatment and recovery.
3. Specialist mental health and alcohol and other drug services establish effective partnerships and agreed mechanisms that support integrated assessment, treatment and recovery and ensure „no wrong door" to treatment and care.
4. Outcomes and service quality for dual diagnosis clients are monitored and regularly reviewed.
5. Consumers and carers are involved in the planning and evaluation of service responses.

To assist services to achieve the above outcomes and as part of the capacity building, the VDDI Education and Training Unit (ETU) was developed and is auspiced by, St Vincent's Health. Under guidance of the ETU Manager and in collaboration with other VDDI partners, the ETU has developed and implemented a state-wide dual diagnosis education and training strategy.

Part of this strategy has been the development and delivery of an on-line dual diagnosis course that is designed to assist the mental health (MH), alcohol and other drug (AOD) and Psychiatric Disability Rehabilitation and Support Services (PDRSS) workforces to become dual diagnosis capable.

Dual Diagnosis Experiential Educators– Job description Page 1 of 2

This position has been developed by the Association of Participating Service Users (APSU) and the Victorian Mental Illness Awareness Council (VMIAC) and the ETU to ensure that the consumers "voice" is heard in the online dual diagnosis course.

BASIC JOB PURPOSE

The position, under guidance of the ETU staff and with support from APSU and VMIAC, will:

1. Develop small online training sessions;
2. Deliver those training sessions; and
3. Evaluate the effectiveness of the sessions.

QUALIFICATIONS

Completed the Online Dual Diagnosis Course
Completed the Online Facilitation Course

Note: Successful applicants will be supported through these courses

KEY SELECTION CRITIERIA

Experience of co-occurring alcohol and/or other drug use problems and mental ill health
Have current capacity to carry out all required functions of the role.
Commitment to completion of training units and delivery of at least three rounds of training
Demonstrated ability to complete the online dual diagnosis course
Demonstrated ability to complete the online facilitation course
Demonstrate ability to communicate knowledge to a group

Accountability

Responsible to:

APSU Coordinator;
VMIAC Director; and
VDDI ETU Manager

Dual Diagnosis Experiential Educators– Job description Page 2 of 2

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