BROADENING THE SOURCE

Fostering family participation in the Victorian alcohol and other drug sector

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

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

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ASSOCIATION OF PARTICIPATING SERVICE USERS (APSU)

APSU believes that people who use alcohol and other drug (AOD) services and their families have a wealth of experience and knowledge. Service users and families have a right to contribute to the running of these services, and to the policies that are made about alcohol and other drugs.

APSU is a Victorian advocacy service of the Self Help Addiction Resource Centre (SHARC) that has been set up to ensure that the opinions and ideas of the APSU membership contribute to service provision, policy, research and professional development.

APSU draws guidance and direction from the APSU Think Tank, made up of service users and family members.

APSU's membership is free and we encourage all service users, family members and service providers to join via www.apsuonline.org.au.

SELF HELP ADDICTION RESOURCE CENTRE (SHARC)

SHARC is a Victorian community-based and not-for-profit incorporated organisation.

SHARC is a peer-based service that is 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 AOD use, with or without mental health issues.

SHARC's mission is to provide opportunities for individuals, families and communities affected by addiction and related problems, to recover and to achieve meaningful, satisfying and contributing lives.

DISCLAIMER

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A WORD FROM THE SHARC CEO

Families have always been important participants of the Alcohol and Other Drug (AOD) sector; their support for their members with substance use issues has been crucial and their advocacy essential.

SHARC was delighted to have the opportunity to develop this manual that not only acknowledges the significance of family involvement in the sector but offers practical guidance and suggestions for how best to engage them in advisory and treatment processes; it provides a way forward.

Many people put their time into the creation of this resource; we received material and feedback from clinicians, their agencies and, of course, families themselves.

I invite you to read the manual, reflect on the history of family involvement and the possibilities, and join us on the journey to full family participation in the delivery of AOD treatment and support for clients and family members.

Heather Pickard

Heather Pickard.

Chief Executive Officer
SHARC

A FAMILY MEMBER'S EXPERIENCE OF PARTICIPATION

In March 2003 I attended an information forum for families and friends that were interested in joining or starting a support group. The first meeting was held the week after and continued on a Tuesday night for the following seven years.

Prior to attending that first meeting I rarely left my home, I did not work, my mental health was suffering, and I felt disconnected from people who could understand my situation. Through the support group I met and established friendships, I felt valued and appreciated.

I became a peer facilitator of this group in December 2003. I attended training for facilitators of support groups. During my time as a family member at Family Drug Help (FDH) I have participated in facilitator training, assisted with the development of the facilitator manual, and have participated in strategic planning days where my voice was heard. My involvement with FDH opened up a range of opportunities to actively participate in the AOD sector.

I wrote a policy proposal for AOD services for families in collaboration with APSU and another family member, made a submission to the review of the Civil Commitment Act of 1968 and have been involved in submissions to the Premier's Advisory Committee on the Inquiry into the misuse of pharmaceutical drugs, as well as the Federal inquiry and review on families and drugs headed by Bronwyn Bishop.

In an attempt to secure funding for a project examining the value of support groups, another family member and I did a literature review, developed a survey for family members and created a proposal for our project. We were not successful in securing funding, but were grateful for the opportunity to try.

I have spoken at a dinner for medical practitioners on the difficulties faced by families and consumers around pharmacotherapies, was invited as a community leader to participate in the Shire of Yarra Ranges Vista leadership program, which resulted in an art exhibition and a book, and participated with Turning Point in developing an eight-week training program for local volunteers who interact with people affected by drugs and/or alcohol. I have spoken about families' experiences at AOD conferences and have participated in interview panels and assessment processes for new job positions.

I assisted the development of the Supper Club, a group specifically for families who have lost a loved one through drug and alcohol use either in an overdose or accident where drugs were the issue. I have always called this 'the silent death' as the wider community is uncomfortable speaking about it. Families now have a safe place to share their grief.

Although FDH is a service for families, many of its programs are staffed by volunteers undertaking roles that in other organisations may be paid. I view them as service providers or workers. In this situation I have provided training to these 'workers'. This to me is family participation at its highest level.

I am currently the chairperson of the FDH advisory committee, a role I am dedicated to. Within the committee is a wealth of knowledge, expertise and skills that are valued by the organisation.

As a family-driven group we have organised two family forums utilising the skills from within the group. Family members identified the need and as a team put together outstanding forums.

I believe family members can participate on many levels without intruding on the core business practices of AOD services.

Marg Quon
Chairperson of the Family Drug Help Advisory Committee

METHODOLOGY

This manual serves as a companion to the publication: *Straight from the Source: A practical guide to consumer participation in the Victorian AOD sector. Straight from the Source* was the first guide to consumer participation in the AOD sector. Its main strength lies in conveying experientially validated approaches on how to meaningfully engage with consumers. Although a small section of *Straight from the Source* is dedicated to family participation, since its publication in 2010 we came to realise that there is need for a more specific resource on how to engage family members of AOD service users in participation activities.

In writing this manual, APSU relied on its own experience with conducting family participation activities, as well as its previous projects and publications.

In addition to this, a literature search was undertaken to find local and international knowledge or tools that directly informed and supported family participation in the AOD Sector.

Data for this manual was also sourced from family member focus groups, forums and surveys, and a number of interviews were conducted with service providers. APSU consulted family members in the development of this manual, asking about their needs, opinions and experiences with consumer participation. Four family focus groups were facilitated and responses to a family survey were incorporated into the manual. Interviews by phone and in person were conducted with twenty-five Victorian AOD Treatment Service Providers.

Constructive feedback on this manual is welcome and can be made at: apsu@sharc.org.au

INTRODUCTION

Since its establishment in 2000, APSU has been collaborating with AOD services across the State, as well as the Victorian Department of Health (DH), to increase consumer participation within the AOD sector. In many instances this work has been fruitful, however there is still a long way to go. Although APSU's initial focus within consumer participation was on service users, it soon became apparent that family members and significant others have an equally important wealth of knowledge deriving from the impact of a relative's or friend's alcohol and drug use. Yet, family members' experience is often different than that of the service users, and thus family participation deserves attention in its own right, while remaining under the banner of consumer participation.

Our aim is to build upon the existing practices of consumer participation by exploring opportunities for family members to be involved in decision-making about priority setting, policy development, education, training, research, service planning, and service delivery in the AOD treatment sector.

Consumer participation – and by extension family participation – is a mechanism for social inclusion and a democratic right. While the latter remains in its infancy in the AOD sector, it is increasingly encouraged in policy, program guidelines and quality tools.

The tools and evidence presented in this manual support the development of a strong and independent voice for family members in the AOD sector through the mechanism of family participation. APSU hopes that this manual can garner broad support from the sector in fostering family participation.

DEFINITIONS

The following definitions are used for this manual:

AOD

AOD stands for “alcohol and other drug”. This acronym is widely accepted and used within the sector. We are using this acronym throughout this manual in different contexts: AOD services, AOD issues, AOD professionals, AOD service users, etc.

AOD TREATMENT SERVICES

AOD treatment services are organisations that are publicly funded to work with people whose alcohol and/or other drug use is problematic. Private services are not included in this definition.

CLIENT

A client is a person who uses or has used a specific AOD service.

CONSUMER

A consumer is someone who uses, has used, is eligible to use AOD services, or is affected by AOD policy and legislation. This includes people who are refused services or who refuse services. It also includes family, friends and significant others of people who are eligible to use services, regardless of whether or not their family member directly uses services themselves.

‘Community member’ or ‘citizen’ are other expressions that correspond to the meaning of the word ‘consumer’ as it is used here.

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.

Consumer participation in the AOD sector consists of including consumers in the decision-making processes around:

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

FAMILY MEMBER

The word ‘family’ or ‘family member’ or ‘significant other’ includes parents, children, siblings, partners, friends or anyone else affected by another’s substance use. Family members are considered consumers because they are community members who are affected by AOD policy, laws, treatment options, workforce training and research.

FAMILY PARTICIPATION (AOD)

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 relative’s behaviour. These complexities demand that family participation is given a degree of separate attention from service user participation.

SERVICE USER

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

PARTICIPATION

The concept of participation is central to democracy. Participation is essential for building and maintaining a cohesive, inclusive and empowered democratic community. In a democratic society citizens have the right to participate in their community and in the decisions that affect them.

Participation is not limited to civic engagements, but includes social participation. This form of participation involves any formal or informal engagement with others[1].

Part One:

Family participation in the AOD sector

RATIONALE FOR FAMILY PARTICIPATION

The rationale for family participation in AOD relies on four 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 valuable contribution and their involvement can lead to improvements in service delivery, policy and research.

1) 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[2]. Statistics from Family Drug Help's Helpline suggest that for each person with a substance use issue an average of 4 or 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[3],[4]. 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.

2) 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.

3) 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 that a service user has: the Australian Bureau of Statistics reported in 2005 that 31,100 children were being raised by their grandparents mainly because of parental AOD issues[5]. The burden of care experienced by families deserves consideration and earns family members a place in decision-making processes.

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

The AOD service system is funded by taxpayers' money to provide a public service to the community. It is therefore part of a larger system of democratic governance. Any decision taken in a democratic system needs to act in the interest of the community, starting with those most directly affected. In a healthy democracy one of the ways used to achieve this is the participation of affected citizens in deliberative processes of dialogue and interaction. Deliberative processes are based on the notion that learning is more than just knowing. 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[6].

As outlined in the previous three premises, 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 the overall improvement.

> Family members are second only to service users in experiencing the challenges of accessing the AOD service system and the service gaps.

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. For examples of existing family participation activities in the AOD sector see Part 3 of this manual.

CONSUMER PARTICIPATION

Although family participation has not yet made much progress, broader consumer participation has grown significantly over the past decade. This is noteworthy in view of the further development of family participation, as having established processes of consumer participation paves the way for involvement of family members.

The Victorian Alcohol and Drug Association (VAADA) developed and administered a sector development survey in 2010 to which 61 agencies responded. Over half of these agencies reported that service users and their families had input into service planning and delivery. The most common forms of participation were consumer involvement in strategic planning days, clinical feedback, client goal setting, suggestion boxes and surveys[7].

In 2011, one year after VAADA's survey, APSU conducted the Strengthening Consumer Participation in the Victorian AOD Sector project. One of the activities of this project was to scope the existing consumer participation activities. The data from the thirty-two AOD agencies that had completed the scoping sheet revealed that most consumer participation activities within the AOD sector are at a low level of participation ladder (information and consultation - see *Straight from the Source,* page 24). A closer look at reported activities revealed that the most common form of participation is at the consultation level through suggestion boxes, practiced by 28 out of 32 surveyed agencies. The suggestion boxes were followed by information level activities, namely the availability of brochures reported by 16 agencies, and existence of a consumer participation related policy or process reported by 15 agencies. Another fairly common form of participation was consultation with consumers in focus groups, which was reported by 11 agencies. All other consumer participation activities were rather rare, although an array of different activities has been reported.

WHY INCLUDE FAMILY PARTICIPATION?

> Creating participation opportunities for family members within AOD organisations has the effect of creating a more inclusive society.

Participation is a way to improve the effectiveness of services and their relevance to the actual needs in the community. Participation also has an empowering effect, because it overcomes the sense of powerlessness that is frequently felt by individuals and communities. Viewed in this way, participation creates healthier and better connected communities[8].

Beneficial effects of participation can be outlined under four main areas:

- Participation strengthens the accountability of institutions by involving individuals directly in decision-making around issues that affect them.
- Participation in decision-making at a local level empowers communities and builds social cohesion, as it gathers individuals around the issues of common interest.
- Participation improves understanding of the existing needs within the community, which leads to increased efficiency in service delivery.
- Participation benefits participating individuals at a personal level, because they gain satisfaction from influencing change in their immediate environment and learn new skills in that process.[9]

Substance use is a complex health issue with broad social implications. Unlike any other health issue, substance use is surrounded 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.

FAMILY PARTICIPATION AS A RIGHT

Consumer participation is an ethical and democratic right. We live in a democracy where we are entitled to vote, however, in itself this is not enough. As citizens we need to have a say by actively participating in policies and processes that effect the most important areas of our lives, like housing, education, health care and employment. In a democracy, every citizen needs to be given the opportunity to have a voice in decision-making around the issues that directly impact his or her life.

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 a part of the treatment process.

FAMILY 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[10]. Social isolation and the feeling of not being heard are commonly part of this experience[11]. People experiencing social exclusion are often left out of decision-making processes that relate to issues directly impacting upon them[12]. Being provided with an opportunity to participate is particularly important for AOD consumers, because their voices are rarely heard in any other political arena. 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.

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 organisation[13].

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[14]. A strong social capital base is an indicator of a healthy, connected and inclusive community[15]. Creating participation opportunities for family members within AOD organisations therefore has the effect of creating a more inclusive society. The absence of family participation as a common practice, on the other hand, makes the AOD sector an accomplice in perpetuating the exclusion of the already excluded families. Social and political inclusion is in line with the therapeutic values and outcomes that the AOD sector is working to sustain. Participation is an important instrument to achieve this.

FAMILY PARTICIPATION FOR CHANGE

Participation and change are intertwining processes. Cultural change is the necessary foundation for meaningful consumer participation, but consumer participation also leads to a cultural and practical change.

Participation is more than a set of practices or policies – it is a learning process. As such, it is dynamic and unpredictable. Learning has a transformative effect on all participants in this process, regardless of whether their role is that of a professional or a consumer[16]. Consumer views may challenge the existing power dynamics, so in order to develop consumer participation to a degree where it is accepted as an organic learning process, there needs to be a cultural acceptance for it within the organisation. Viewed in this way, participation is an end in itself – it is a cultural shift towards inclusion of different perspectives in the priority setting and decision-making. Just as a child becomes aware of the others' needs and perspectives as it matures, so an organisation demonstrates its maturity by developing the ability to include the views of the community that it serves.

Participation also 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 a 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 the 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.

> Families are an unofficial, silent partner in the AOD service provision.

FAMILY PARTICIPATION AS AN INSTRUMENT OF ACCOUNTABILITY

Participation is a way to ensure that AOD services, as well as health services in general, are accountable to the community they serve[17]. This is the main and most direct way to ensure that service provision is meeting the needs of the community. 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 need of the community.

FAMILY PARTICIPATION AS POLICY

A body of policy has been developed to support consumer participation in Victoria. Family participation is also supported in these policies.

In 2006 the Victorian Government issued the policy document *Doing it with us not for us*[18], which outlined the necessity and importance of consumer participation in the Victorian health services. The document refers to 'consumers and carers', thus giving a specific role to family members. While the term 'carer' does not fully reflect the role of a family member in the AOD context, this document is strongly focused on including family members in caring roles in decision-making processes. So although *Doing it with us not for us* does not speak specifically about complexities of the AOD context, it remains a valuable policy, as it provides a basis for consumer participation across the health sector, and the significance of family participation is acknowledged throughout the document.

Dual diagnosis: key directions and priorities for service development[19], published in 2007, documented the five main outcomes that needed 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. The fifth outcome states that a major involvement of consumers and carers is needed in the planning and evaluation of the services. This document continued using the term 'carer', but it also acknowledged the diversity of circumstances by using the more detailed terms 'clients, families and carers'.

In 2008 Victorian Government issued *A new blueprint for alcohol and other drug treatment services 2009-2013*[20], 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.

The vision of a client-centred service system was further reinforced in Victoria with the publication of *Shaping the future: the Victorian alcohol and other drug quality framework*[21] in 2008. This document outlined six quality standards for the AOD sector. The first standard was *Consumer focus*, which recognized that consumer participation is a critical component of a client-centred service system.

The 2011 Victorian Auditor General's (VAGO) report on AOD treatment services was highly critical of various aspects of the AOD treatment system[22]. One of the criticisms was directed at 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*, published by the Victorian Department of Health in 2012[23]. This document stated that the AOD sector reform was going towards a person-centred, family-inclusive and recovery-oriented system. The person-centred 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[24].

New directions for alcohol and drug treatment services: A roadmap was released as part of a larger Victorian AOD strategy, which was outlined in more detail in *Reducing the alcohol and drug toll: Victoria's plan 2013 – 2017*, published a few months later[25]. This policy supported the *Roadmap's* vision of a person-centred and family-inclusive system, while documenting the Victorian Government's commitment to strengthen the involvement of AOD service users and their family members in policy development and service delivery. Most importantly, the document stated that 'it is crucial that the government clearly listens to the voices of people with drinking and drug problems, people who have recovered from those problems and their carers and families'[26].

This brief chronology of AOD policy shows that the importance of service user and family involvement has progressively gained recognition within the governmental policies around the AOD sector. The complexity of the AOD context has also been increasingly recognised, which was reflected in the language (e.g. differentiation between families, carers, children, significant others etc.), as well as in the acknowledgment that families themselves need support in many different ways. Finally, Victorian Government in collaboration with the AOD sector and consumers developed a set of *Victorian alcohol and drug treatment principles*, which were 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.'[27]

The significant presence of service user and family participation in the government policy is not necessarily reflected in organisational policies. We do not have the exact 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. Nonetheless, this is not a uniform picture, but there are variations from one organisation to the next.

A policy framework specific to consumer participation in the AOD sector would be a beneficial addition to the previously listed body of policy. Thus far *Doing it with us not for us* has been considered a document that provides guidance for the development of consumer participation across the health sector. While much of this document is helpful, it does lack the insight into complexities specific to the AOD context. Tensions in the relationships between service users and their family members, as well as stigma and criminalisation are some of these complexities and they must be taken in consideration when developing consumer participation in the AOD sector.

An AOD specific policy framework would also allow the development of a strategy for the implementation of consumer participation within the AOD sector. During a project conducted in 2012 APSU learned that consumer participation in the AOD sector is inconsistent and generally at a rather low level (see page 21). This revealed a significant discrepancy between the policy and practice of consumer participation.

An AOD-specific consumer participation policy framework would represent an essential stepping-stone in bridging this discrepancy.

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. 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. *Straight from the Source* – Part 2 (pp.43-49) offers a guide on how to develop a consumer participation plan that suits any individual organisation.

> Service users, service providers and family members share the same problem, but experience it in different ways.

At the same time there are some overarching principles that should guide any practice of consumer participation. The key words here are uncertainty, trust, relationship and dialogue. Consumer participation needs to be built as a relationship of equals between consumers and service providers. It has to be an open dialogue where each participant is respectful of others and everyone has the opportunity to express themselves. As such, it carries a high level of uncertainty, just like any democratic process. 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.

5) Consumer participation must be supported from the top down, but it is built from the bottom up.

6) It's all about relationships, so use and build people skills.

7) Consumer participation needs partnerships, partnerships need dialogue, dialogue needs trust. So build trust.

8) Multiple strategies work better[28].

Consumer participation ultimately creates a shift in power relations, and for this reason it requires a cultural change. Control of an organisation depends on its governance structure. Typically a board of directors is at the top of the structure, followed by the CEO, management and staff. An organisation needs to think how consumers fit in this scheme.

Every governance layer has a degree of power, but typically every layer has more power than consumers. In planning consumer participation an organisation should have an open discussion about those power relationships[29]. This exercise will enable the organisation as a whole to come to an understanding about how consumers can participate in the existing power relations. The cultural change necessary for meaningful consumer participation is gradual and takes time. Some professionals are likely to resist this change. The processes supporting consumer participation need to be developed so that they enable consumers to enter the governance structure in a range of subtle ways. This can help in overcoming resistance from some professionals, but support from high-level management is crucial in this process. In most organisations it is not realistic for consumers to take complete control. The goal should rather be to build a partnership between consumers and professionals.

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. Direction and modalities therefore cannot be predicted, but stability of the process can be ensured by a commitment to the underpinning values. These can be gathered from the principles in *Doing it with us not for us*[30].

1) Trust • Participation works best where there is mutual agreement of the processes and assessment of the issues under consideration as developed through productive working relationships.

2) Respect • All participants need to show consideration and value each other as equal contributors to the participation process.

3) Openness • Participation must be built from the ground up and this can only be ensured if all participants are open to considering the ideas of service users, family members and the community and are willing to accept change.

4) Equal opportunity • At the earliest possible time, involve all those who will be affected by the decisions, inform them of the decision making process and ensure they have access to the information and the means to participate.

5) Advocacy and support • Participation must be supported from the top and resourced so that participation is meaningful for the consumer.

6) Responsiveness • The capacity to undertake participation requires skilled organisations and benefits from multiple strategies and resources.

7) Shared ownership • All involved share ownership of the process and decisions and are responsible for monitoring and evaluating the impact and outcomes. How the responsibility is distributed should be defined as part of the participation arrangement.

8) Dissemination • The decisions made, and how consumers, carers or community members' participation influenced those decisions, should be communicated to all those involved and affected by the decisions.

9) Evaluation • Lessons learnt from the participation process should be identified and communicated as widely as possible.

COMMON BARRIERS TO FAMILY PARTICIPATION

So far in this manual we have described a number of ways in which family participation can benefit the AOD system and individual organisations. Benefits of broader consumer participation have also been described in *Straight from the source*, pp. 19-20. However, before and even after achieving the beneficial impact of community involvement, many organisations will experience a number of barriers. This cannot be entirely avoided and needs to be accepted as a learning journey. Also the specific setup of each organisation or program will bring up specific barriers. Nevertheless, we have identified a number of issues that commonly come up in the process of establishing family participation.

ATTITUDES

Service Providers

By the very nature of treatment services professionals are in charge of the process. They assume the role of the expert and problem fixer. This is not an imposition, but rather the expectation of people who come to services for help. When developing consumer participation this relationship can easily become a barrier, because consumer participation requires equality amongst all the participants, whether they are service providers, service users or family members. If service providers approach consumer participation as the experts that have the best knowledge about how to deal with the AOD issues, the outcome is likely to be a tokenistic model of participation. Professionals with such an attitude will conduct some participation activities because there is an expectation to do it, but they may not see the value of it and could miss the opportunity to seize the of the process.

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". While the statement in itself is not inaccurate, it is however irrelevant in regards to participation. The second view is that families are overburdened by the problems associated with their relative's substance use. Providers with this view may approach families as helpless victims that have no resources to deal with the problems they are facing and are in desperate need of professional expertise. While these two views of families are very different, they have a disempowering effect and miss seeing the value in the experience of a family member.

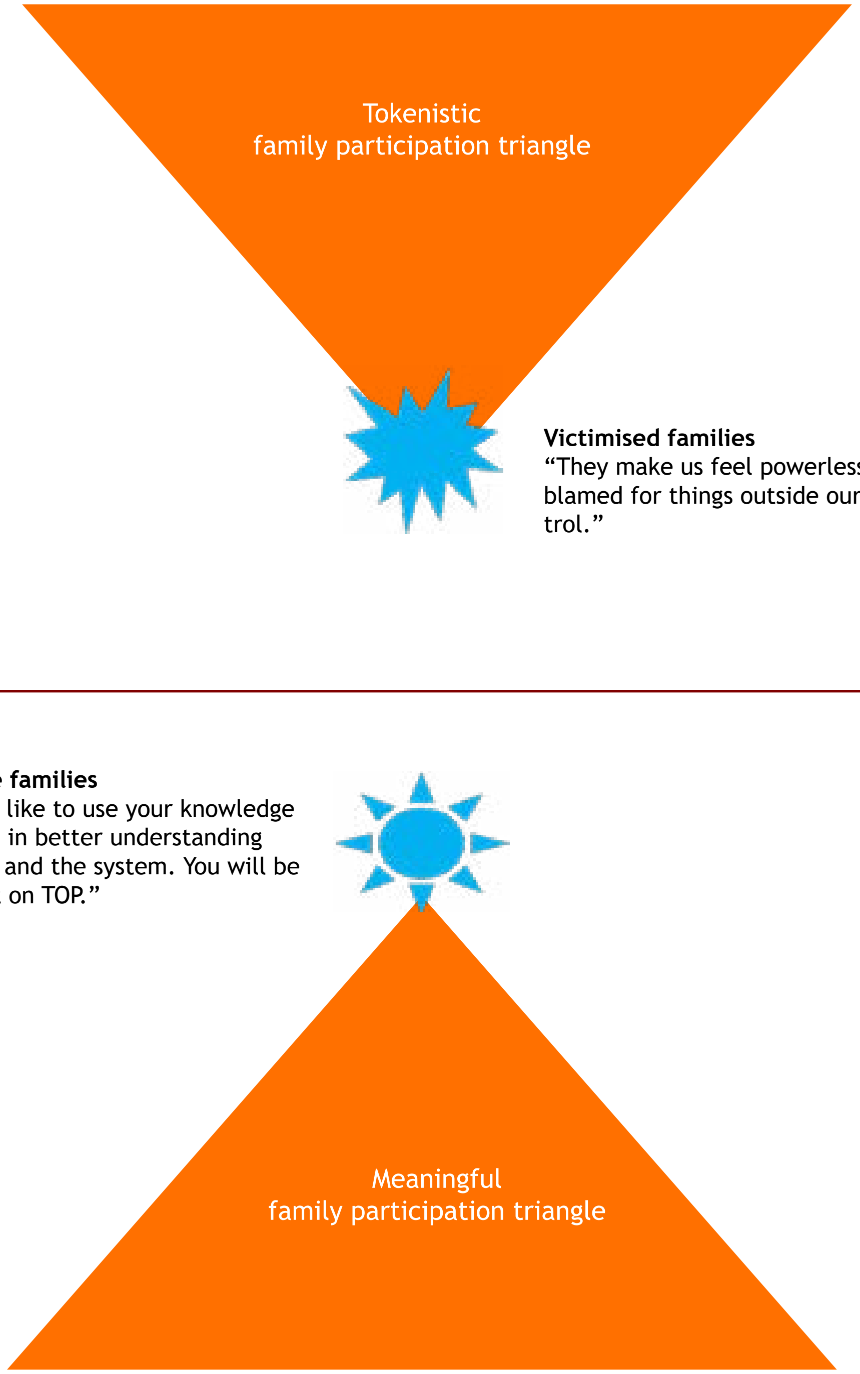
Therefore a shift in relationship is necessary whereby professionals use their knowledge to assist service users and family members, but their contribution is not to be considered superior - they are on tap, not on top. Meaningful and tokenistic family participation triangles (page 30) illustrate the 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 the 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.

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 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, p.492.

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, as well as 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.

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. This is not an entirely incorrect assumption. For example, the argument could be made that any particular member of the Parliament is also not entirely representative of their community, yet we do not question the democratic processes of representation. Certainly 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.

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 that 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.

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 of 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 have a 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, the view that drug use is a crime issue is still dominant in our society. Consequently, some people still believe people with drug addiction have brought their troubles upon themselves and 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.

> Organisations should approach and motivate family members, and make them feel welcome in providing their input.

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. It is, therefore, important to create a safe space for family participation and to develop a culture where staff and management welcome consumer views.

LACK OF RESOURCES

Development of consumer participation requires time and other resources; service providers often report that they lack the capacity to engage with consumers at a meaningful level. This is a valid concern, however, if consumer participation is considered a low priority, for any reason, it is unlikely to occur. Some organisations have developed creative ways to overcome resource limits whilst others, even with the means, have not managed to engage effectively with their consumers at all.

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.

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 or under-preparation. Over-preparation refers to a process where the final decision has been made before involving consumers, whereas under-preparation is when consumers are not given sufficient information to be able to form an informed view on the question at hand[31]. Tokenism is discouraging for family members, as it reinforces the sense of powerlessness and devalues their lived experience.

Part Two:

A plan for organisations

A PLAN FOR ORGANISATIONS

In this part of the manual we aim to provide practical advice specifically 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. Family members and service users experience substance use issues in different ways, and consequently have different perspectives. These differences have an impact on how family members and service users engage in consumer participation.

This section of the manual starts with some suggestions concerning the acknowledgment of the value of family members' experience in treatment, as well as their need for treatment in their own right. We then go on to look at the importance of information provision and organisational policy. The section concludes with some suggestions for participation activities for family members.

LAYING THE GROUND FOR FAMILY PARTICIPATION

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. APSU can support organisations in this process and *Straight from the source* – part 2 (pp. 43-49) provides practical guidance in setting up consumer participation.

Many organisations find it problematic to engage families because they do not provide any treatment or support services for family members. 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. Every service provider should evaluate what step of the process is the best time to ask this question. It can be addressed at the beginning, i.e. during the assessment, and, if the service user is not ready at that time, the question should be raised throughout the treatment journey. Clients need to have the ultimate say regarding involvement of their family, i.e. when this involvement 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 might bring to the entire experience. Unlike peer support groups or professional support, inclusion in individual treatment plan represents consumer participation at a very basic level.

PROVIDE PEER SUPPORT GROUPS FOR FAMILIES

Peer support has an empowering effect on individuals who feel overwhelmed by facing a problem in isolation. Peer support groups are successful in overcoming the stigma and isolation related to drug use in the broader society. 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 very small investment from the organisation. The group needs little more than a space for meeting and a worker to act as a liaison to induct peers in organisational policies that are relevant to them. SHARC can provide assistance with the group set-up and train the peer facilitators.

Accommodating a family support group gives a clear signal that the service provider acknowledges the experiences of family members impacted by substance use. This acknowledgment creates a climate in which family members are more eager to engage with the organisation and, consequently, allows service provider to access family members that may be interested in participation activities.

There is a common misconception in the AOD sector that peer support is a form of consumer participation. This confusion is probably due to the fact that both peer support and consumer participation share the view that life experience is a form of expertise. The two concepts, however, have 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, therefore the character of peer support is therapeutic.

OFFER PROFESSIONAL SUPPORT FOR FAMILIES

Creating a working relationship with specialised services that work with families impacted by substance use will assist effective referrals for family members who would benefit from professional support. This collaboration 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.

CONSIDER:

- The purpose of family inclusion is to benefit the clients' outcome. Clients have the ownership of their process of recovery and the ultimate say in their family's involvement.
- Does your organisation give clients the opportunity to have their families involved in their treatment? If not, consider at what points of treatment this opportunity can be offered.
- What forms of family involvement in treatment are realistic for your organisation.
- Even a minor family involvement can be very beneficial. For example, giving family members regular updates on treatment progress can help client recovery.
- Connect with organisations that work with families of people who use drugs and alcohol, such as Family Drug Help (FDH) or Family Drug Support (FDS). FDH can suggest options for support of family members.
- FDH has a statewide network of support groups for family members. If your organisation lacks resources to host a support group, you can suggest an FDH group to your clients' family members.

INFORMATION

Information is a very important element of consumer participation. It is particularly important 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, it will 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 service user will be doing, the day-to-day operations of the service, how a family can support the service user, the relevant policies of the organisation and support available to family members.

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 and Family Drug Help helpline.

HOLD INFORMATION SESSIONS AND EVENTS

Information sessions offer a 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.

CONSIDER:

- 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 can be your first step.
- Survey family members to gather what topics they would like to learn more about. Propose a list of topics and invite family members to suggest any topics of interest that are not on the list.
- Involve your clients in the development of information for families. Service users have an idea of how a program works, so they are likely to have a better idea of what their families should be informed about.

POLICY

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.

DEVELOP CONSUMER PARTICIPATION POLICY

The value of family experience should be acknowledged in an organisation's consumer participation policy. An example of a consumer participation policy that encompasses family participation is available on page 54.

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. 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.

It is currently not customary in the AOD sector to have a separate charter for family members, although it is a common practice within the mental health sector. APSU recommends that the family members' charter be developed, particularly in those organisations where the treatment program puts specific limitations on relationships between clients and their family members. A family members' charter can help clarify that the service user has the choice over how much involvement a family member will have, or that a family member should not interfere with the treatment program by organising family activities during program hours.

INFORM FAMILIES OF THE LOCAL COMPLAINTS PROCEDURE

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

CONSIDER:

- Involve service users and family members in conversations about policy.
- Open a discussion about the role of your clients' family members. How do they see themselves? How do clients see them? How do staff members see them? Consider the differences between the terms carer, family member and significant other. The variety of views will enrich your policy.
- Consider the template for a family inclusive practice policy available in NADA's Tools for Change[32].
- Discuss family members' rights and responsibilities with your clients, their families and staff. These conversations will indicate if there is need for a specific family members' charter of rights and responsibilities and what it should contain.

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.

Each of these activities can be planned and divided into the following stages:

1) Preparation

This should address some main questions:

- ○ What is the purpose of the activity?
- ○ Does the activity require any financial resources?
- ○ How will the activity be executed?
- ○ Who will be driving the activity?
- ○ Who will be supporting the driver?
- ○ How much time will the activity require?
- ○ How many participants would make for the optimal outcome?

5) Recruitment of family members

This can be done through organisational networks or through APSU. During this stage family members should be briefed about the process and questions likely to be used.

6) Training

Training can be delivered to build a pool of family members for a number of future activities, or it can be tailored for a specific activity. Some activities (suggestion box, surveys and focus groups) do not require training, but higher-level activities (advisory groups or membership on a committee) do. Training should contain information about the organisation's programs, processes, policies and structure; as well as generic content relevant for consumer participation. The *Experts by experience* section in APSU's *The peer model manual* (pp. 70-96) provides step by step guidance to develop and deliver consumer training. APSU also delivers this kind of training.

7) Execution

This is 'when' the activity takes place. While this is the central part of the activity, it should not be confused with the activity as a whole.

8) Analysis

This is the post-production of the participation activity. During the analysis an organisation explores if and how family members' input can be implemented.

9) Feedback to family members about the results of the activity

Feedback is essential for meaningful family participation. Following the analysis, an organisation needs to inform family members on how their input is being actioned or why it is not being actioned. Some activities will require that feedback to family members be repeated at various stages. Informing family members about the effects of their participation extends family involvement beyond the execution, thereby helping to avoid tokenism.

10) Implementation

This is the process of actioning suggestions gathered from family members.

11) Evaluation_of implemented suggestions

This concludes the activity and provides an evaluation of the learning process.

SUGGESTION BOXES

This form of feedback mechanism should be available for both 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. Family members should be explicitly included in the invitation to leave a suggestion or a comment about their experience of the service. Feedback about implementation of suggestions and comments should be available to all service users and family members. For example, it can be placed on a notice board in the reception area.

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.

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;
- Suggestion boxes gather only the views of those people who are inclined to give suggestions, thereby missing on many who are less inclined to do so.

SURVEYS

A survey is a simple way of collecting information from a large number of people. While a survey does not allow in-depth engagement, it is an efficient way to reach a large number of family members, including those who may not want to engage in a more demanding form of family participation.

Surveys can be designed for a range of different purposes. Some surveys are designed specifically for clients, e.g. the exit survey or a survey about a specific program; others may be designed for families regarding issues that do not require specific client experience.

When conducting a survey, it is important to be clear about its purpose and to convey it to the surveyed consumers. It is equally important that the data gathered through a survey is then used in some way. Conducting a survey with consumers without acting upon the gathered information is tokenistic and contrary to the purpose of consumer participation. The process should be concluded by a communication about any action 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.

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.

FOCUS GROUPS

In some respects, focus groups are similar to surveys, as both modalities are focused on gathering community views on a specific topic. For example, they can be useful in gathering consumers' views in relation to the start of a new program or service, specific policy issue or a problem in the community. However, focus groups 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.

These two forms of consultation can also be combined, so that an initial survey helps 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 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.

Family members can be included in broader focus groups with service users. An example of a successful focus group with family members is on page 56.

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.

ADVISORY GROUPS

Consumer advisory groups or committees are increasingly present in the AOD sector; they can be an effective form of family participation.

Some advisory groups are not suitable for family members. For example, many programs have consumer advisory groups specifically to allow clients of the program to discuss different issues and come up with suggestions for improvements. The ownership of the group in this case is clearly with service users and introducing a third party, whether family members or service providers, would severely disrupt the group dynamics and power relations.

Some advisory groups are set up to provide input in 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.

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.

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.

FAMILY REPRESENTATIVES ON COMMITTEES

Consumer representation on committees is fairly common in the broader health sector, but it is still scarcely practiced in the AOD sector. While there are some examples of service users on committees, inclusion of family members is very rare. 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 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 member's 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 a 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 under 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 from 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. APSU also provides training, which prepares both service users and family members for involvement in participation activities.

CONSIDER:

- 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.
- Refer to the principles of participation from page 29 as you go.
- 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:

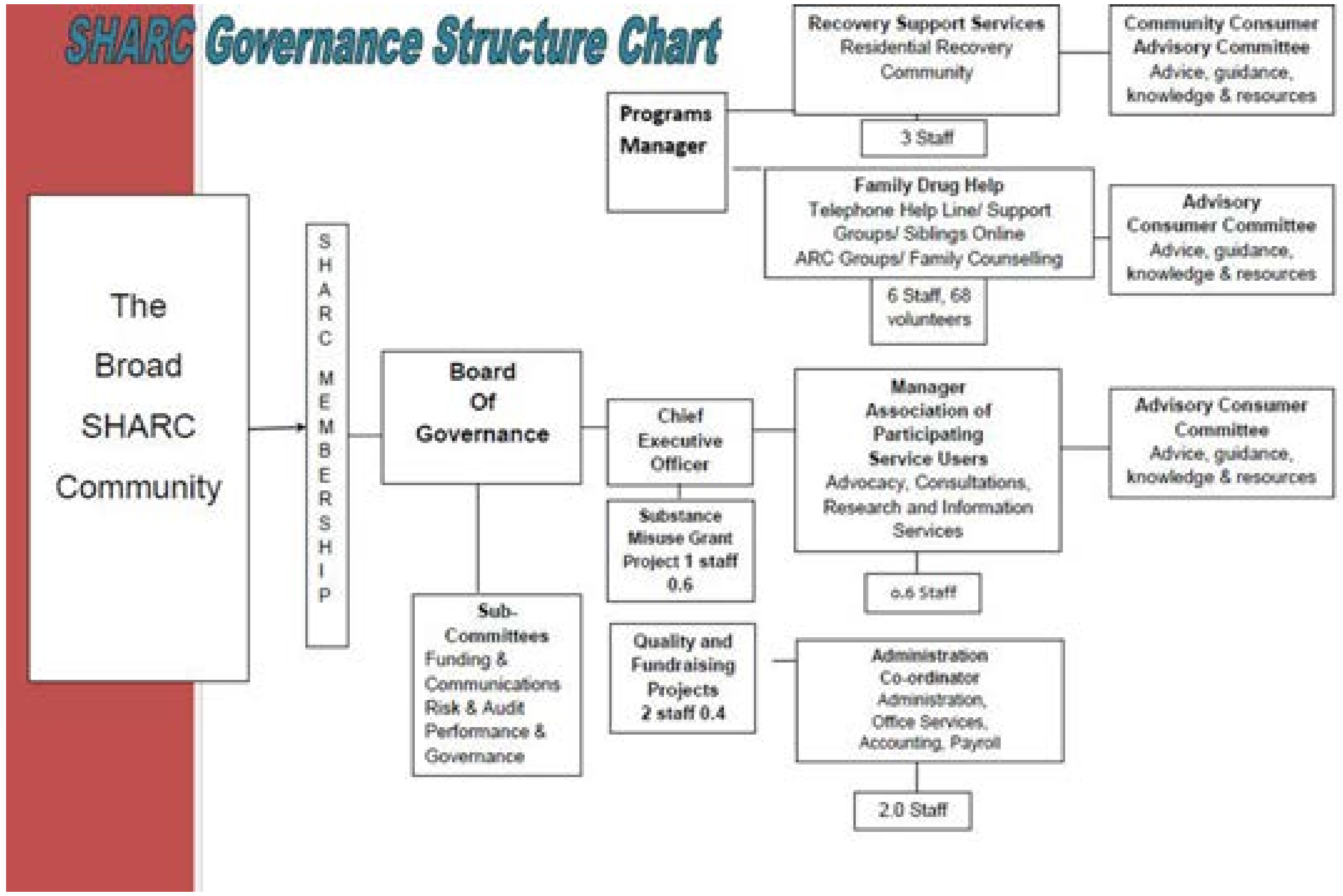
Examples of successful family participation activities

EXAMPLES OF SUCCESSFUL FAMILY PARTICIPATION ACTIVITIES

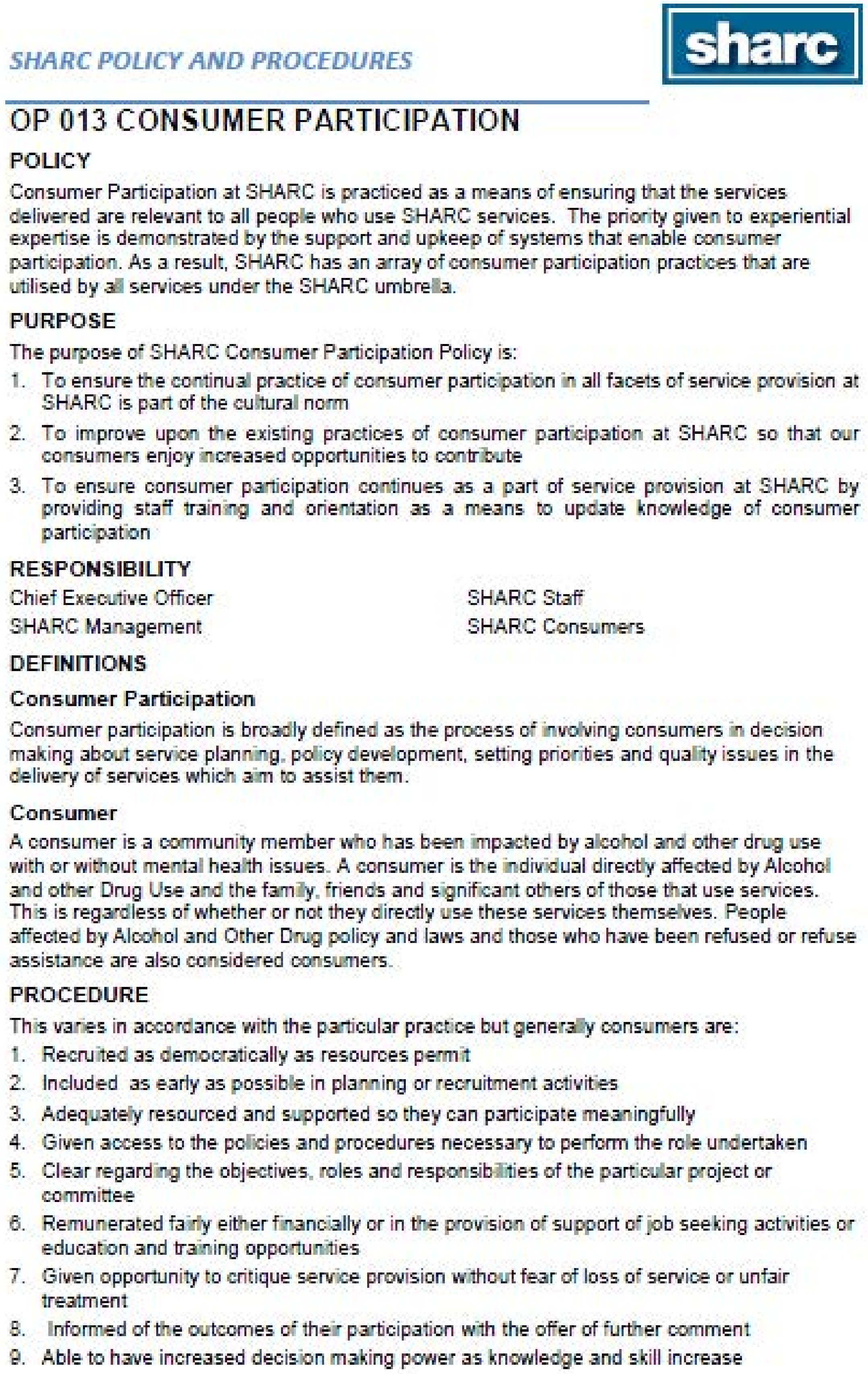
For this part of the manual we have chosen a few illustrations of successful family participation. Since family participation is still a relatively new practice in the AOD sector, we had a rather scarce pool to choose from. Nevertheless, the following pages feature stories of family involvement, which cover various examples ranging from consultation (ReGen's Methamphetamine Family First Aid program) to partnership (advisory group for ice education project).

GOVERNANCE STRUCTURE

Self Help Addiction Resource Centre (SHARC) is the umbrella organisation for three main program areas: Recovery Support Services (RSS), Family Drug Help (FDH) and Association of Participating Service Users (APSU). Each of these program areas has a consumer committee that provides advice and guidance on a range of issues around day-to-day business. RSS Consumer Committee is entirely composed of current clients residing in RSS managed properties. FDH Consumer Committee is composed of family members and a minority of AOD professionals. APSU Consumer Committee is composed of service users and family members. Each of the three committees is in direct liaison with the program manager.



CONSUMER PARTICIPATION POLICY INCLUSIVE OF FAMILY



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 Management
SHARC Staff
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

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 to provide advice to FDH on a variety of program related topics, the committee members are eager to improve the understanding of AOD issues within the community. This motivated them to embark on organising community information forums, as a project of their own, relatively independent from FDH, although supported by a program manager and staff.

Choice of the 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 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. But an even greater success was the ripple effect that followed the events. This included 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.

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 notes 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

This session was attended only by family members. Input from this group was not only invaluable regarding the final shape of the program, it 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 to this, the group insisted on information being added regarding safety plans and more realistic examples regarding 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.

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 guides 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 plan to extend this involvement at a later stage in 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 the educational materials that are user friendly; family members made suggestions, which could not have been made by a professional expert. Thus 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.

SERVICE USERS AND FAMILY MEMBERS WORKING TOGETHER

Southern Region Community Advisory Council (SRCAC) and Eastern Region Dual Diagnosis Consumer and Carer Council (ERDDCCC) have both been successfully operating for a number of years with a mixed membership of service users and family members. We include the SRCAC Terms of Reference, developed by SRCAC members.

Terms of Reference V 1.3

1. Background

Consumer participation in the Alcohol and other drug sector (AOD), despite being a key policy directive, is lagging behind that in other areas of health and community services. The Southern Region of Victoria's AOD service system is no exception. The Department of Health Southern Region has funded the Association of Participating Service Users (APSU) at the Self Help Addiction Resource Centre (SHARC) to work collaboratively with Southern Region service providers and consumers to set up a consumer group to assist services in the region to increase their consumer participation. That group has been named the Southern Region Community Advisory Council, or SRCAC.

2. Function of the Southern Region Community Advisory Council (SRCAC)

The Southern Region Community Advisory Council (the Council) will be a vital and effective forum for participation in service provision and policy development in this region. The Council has three primary functions;

2.1 the Council can be used by service providers in the region to obtain consumer feedback regarding information provision, service practices and programs, service development and evaluation as well as providing suggestions for their improvement,

2.2 the Council will be available to provide input into regional alcohol and other drug issues and policy,

2.3 the Council may form partnerships with services to improve their consumer participation.

3. Role of the Southern Region Community Advisory Council

3.1 The Southern Region Community Advisory Council will focus on improving AOD services in the Southern Region for the benefit of the community by consulting and collaborating with AOD service providers and consumers[1] from the region.

3.2 The SRCAC will provide consumer feedback in relation to service delivery and quality improvement.

3.3 The SRCAC will promote consumer participation in the SMR.

3.4 The SRCAC will develop processes to measure outcomes of their work and establish feedback protocols.

4. Name of Association

The association shall be called the "Southern Region Community Advisory Council" (hereafter referred to as "SRCAC").

5. Definitions

'Consumer' means anyone eligible to use alcohol and other drug services and includes their family, friends and significant others.

'AOD' means Alcohol and Other Drug

6. Vision

SRCAC envision a world where recovery from addiction to alcohol and other drugs is understood, promoted, embraced, and enjoyed; and where all who seek it have access to the support, care, and resources they need to achieve long-term recovery.

7. Core Purpose

To improve AOD services in the Southern Region for the benefit of the community by consulting and working in partnership with AOD service providers and consumers from the region.

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[1] A consumer is anyone eligible to use alcohol and other drug services and includes their family, friends and significant others.

8. Aims and Objectives

8.1 To improve alcohol and drug services in the Southern Metropolitan Region (SMR).

8.2 To provide consumer feedback to services in SMR.

8.3 To promote consumer participation in SMR.

8.4 Will develop processes to measure the outcome of its work.

9. Values

9.1 We embrace and promote recovery in individuals, families, and communities.

9.2 We respect that there are multiple pathways to recovery.

9.3 We recognise the interconnectedness of individuals, families, and entire communities.

9.4 We value the practice of volunteerism, service, and partnership.

9.5 We strive to end fear, ignorance and prejudice against people in or seeking recovery.

9.6 We believe that all people deserve to be treated with dignity, respect, and fairness.

10. Qualifications for Membership of the Council

Membership of the Council is open to past and present consumers of AOD services in the Southern Metropolitan Region of the Victorian Health Department who are able to demonstrate a commitment to the work of the Council, and a capacity to fulfil the requirements of membership.

11. Composition and Membership of the Council

11.1 The Council will consist of ten members:

a) Five consumers with personal experience of AOD service use; and

b) Five consumers with family experience of AOD service use

c) This may be varied to six of one group and four of the other when deemed desirable by the Council

11.2 The Council has the following Office Bearers:

a) a Chairperson

b) a Secretary

11.3 The Council shall appoint the Chairperson and a Secretary from among its members for a period of 1 year.

12. Recruitment of Council Members

12.1 A Register of people interested in serving on the Council is to be kept by the Chairperson and Secretary

12.2 When a vacancy arises, the Council may interview those on the Register of interested people and/or advertise the vacancy through means such as notices at Agency premises, etc.

12.3 Interviews are to be conducted by 2 Council members and 1 member of the Steering Committee.

13. Appointment of Council Members

13.1 Council members are appointed for an initial term of twelve months

13.2 A second twelve month term is granted automatically should the member desire it.

13.3 If a third term is sought, the Council member must reapply for membership.

13.4 Council members serve a maximum of three consecutive terms

14. Suspension or Expulsion of Council Membership

14.1 A member who fails to attend 2 consecutive Council meetings without communicating an apology will be deemed to have resigned from the Council, and their position will be declared vacant at the next Council Meeting.

14.2 The Council may remove a member from their position on the Council if they are deemed to have acted contrary to the Council's Code of Conduct.

14.3 Any person removed from their position has recourse to the Council's Disputes and Grievances processes (Item 17 of these Rules)

15. Chairperson

15.1 The Chairperson is responsible for the Council's adherence to these rules, and chairs Council meetings.

16. Secretary

16.1 The Secretary is responsible for keeping Minutes of Council meetings and performing other duties imposed by these rules.

16.2 The Secretary will distribute Minutes of a meeting to all Council members one week after the meeting being held.

16.3 The Secretary prepares the Agenda for Council meetings and must include any items submitted by Council members.

17. Subcommittees, Project Teams, Task Groups, Working Group

17.1 When required, the Council will create groups to work on specific issues or tasks. Each group so formed will be governed by the rules of the Council and will have:

a) A convenor, responsible for
  - arranging meeting times,
  - booking venues,
  - advising group members of meeting details.

b) A member nominated to record proceedings and prepare any progress reports for Council (the note-taker).

c) A statement from the Council describing;
  - the role of the group,
  - the names of the convenor and note-taker,
  - the frequency/number of meetings to be held,
  - a time frame for any deliverables the group is responsible for, and
  - an end date for the group.

17.2 The group shall report its progress to each Council meeting.

18. Council Meetings

18.1 The Council will meet at least 11 times a year.

18.2 The Chairperson or at least half the Council members may convene a Council meeting at any time.

18.3 At a Council meeting 50 percent plus 1 of active[2] Council members shall constitute a quorum.

18.4 Decision making by the Council is to be by consensus, anyone who disagrees with a decision may, at their request, have their dissent recorded in the minutes.

18.5 Two members of the Steering Committee are invited to attend each ordinary Council meeting, although they do not contribute to the establishment of a quorum.

19. Rules of Association

The rules can be changed at any duly constituted Council meeting.

20. Disputes, Grievances and Mediation

20.1 In the first instance, an effort to resolve any issues between Council members should be made by the individuals concerned before the next Council meeting.

20.2 If the outcome is unsatisfactory to any party the issue should be placed on the Agenda of the next Council meeting for deliberation. If the Chairperson or Secretary are involved in the dispute they are to relinquish their roles until the issue is resolved.

20.3 In the case that the issue cannot be resolved at the Council meeting, the complaint can be referred to the SRCAC Steering Committee by the person chairing the meeting.

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[2] Active members excludes those on leave of absence, Steering Committee members, or other observers.

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