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

STRAIGHT FROM THE SOURCE

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

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ACKNOWLEDGMENTS

Enquiries about this publication should be directed to:

ASSOCIATION OF PARTICIPATING SERVICE USERS (APSU)

APSU believes that people who use alcohol and other drug services have a wealth of experience and knowledge to contribute: service users and family have a right to have a say in how these services are run and what policies are made about alcohol and other drugs. APSU is a Victorian advocacy service of the Self Help Addiction Resource Centre that has been set up to ensure that opinions and ideas of people who use alcohol and other drug services contribute to service provision, policy, research and professional development. APSU draws guidance and direction from a steering committee, made up mostly of consumers and is staffed by consumers. APSU's membership is free and both consumers and service providers are encouraged to join via www.apsuonline.org.au

SELF HELP ADDICTION RESOURCE CENTRE (SHARC)

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

SHARC is a Victorian, community based, 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 alcohol and other drug use with or without mental health issues.

FOREWORD

The participation of consumers in alcohol and other drug (AOD) services is an idea whose time has come. At its most elementary, the relationship between a person with an alcohol or other drug issue and a clinician, care worker or support worker has to be a partnership if it is to produce beneficial results. However wise, insightful or skilled a practitioner may be, it is up to the individual, with his or her own resources and expertise in the context of their lives, to make good use of the clinician's advice and care and translate that into something worthwhile. Corresponding to this at a service or organisational level, service users themselves have unique insights and expertise that should be considered invaluable in determining what services are available, how appropriate they are to the needs of the communities they serve and whether or not they are of adequate quality.

In 2010, the validity and need for consumer participation in AOD services is no longer up for debate. It is questions around how to develop consumer participation and what it will look like in our services that can still take the wind from our sails. The AOD sector is highly diverse, which means that there cannot be one simple blueprint, but it is also a highly creative and responsive community of service users and service providers. Now is the time to bring together what is useful from consumer participation in other areas of health and social development with what pioneers in our own alcohol and other drug sector have learned over the years. Straight from the source brings all this together for us and provides the building blocks and tools for our own endeavours. The broad policy supports are in place. Now is the time to build our partnerships for the future!

Damon Brogan
Executive officer
Harm Reduction Victoria Inc

A WORD FROM THE SHARC CEO

This practical guide is a significant milestone in consumer participation for our field. Now is the time for the next step. It is realistic and necessary that we as services seek, engage and respond to the information offered by the service users about the direction and impacts in their lives, and how our services can best assist them.

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

I am heartened to observe the courageous work already occurring within our field. SHARC is proud to present to you *Straight from the source: A practical guide to consumer participation in the Victorian alcohol and other drug sector.*

Heather Pickard
Chief executive officer
SHARC

INTRODUCTION

There has been considerable effort and success on the part of alcohol and other drug (AOD) services and the Victorian Department of Health (DH) in developing consumer participation practices within the sector. However, consumer participation in the AOD sector is still lagging behind that of the health and mental health arenas. Many participation activities are isolated, ad hoc and often occur at the lowest levels of involvement.

Although the Department of Health regularly includes consumer participation statements in its policy documents there has been little direction for services on how to go about the complex yet rewarding task of engaging consumers. Furthermore, there has been little training delivered to service providers and virtually no resources with which to implement participation strategies.

In writing this handbook, the Association of Participating Service Users (APSU) has sought not only to gather the theory of consumer participation in the alcohol and other drug sector but also the practice. Although other guides to participation exist, this is the first to be written solely by consumers. It conveys experientially validated approaches to engaging with service users and their families to produce meaningful consumer participation.

Straight from the source draws on current literature, input from consumers and service provider focus groups and APSU's own experience in conducting consumer participation activities to provide a comprehensive guide to participation in the AOD sector. The first section is a discussion on consumer participation and how it can be applied to the sector. The second section includes a consumer participation plan for organisations and the third section contains an extensive range of real life examples of participation activities across AOD services, training, policy development and research.

APSU anticipates that this handbook will be used by the alcohol and other drug sector in the development and implementation of significant and sustainable consumer participation.

HOW TO USE THIS HANDBOOK

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

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

- Read through in chronological order
- Choose a topic of interest from the contents page
- Look at *Part two: A plan for organisations* beginning on page 43 for ideas on how to move forward in your organisation
- Select practical examples you are interested in from Part three

CONTENTS

PART ONE:

Consumer participation in the alcohol and other drug sector

PART TWO:

A plan for organisations

PART THREE:
Practical examples of consumer participation

DEFINITIONS

The language used to describe people can be problematic. For example, a patient is someone who sees a doctor, a client is someone who needs help and a consumer is someone who purchases products from the free market. All terms have their advantages and disadvantages; nevertheless, language must be used.

These are the definitions used for this handbook:

CONSUMER

A consumer is someone who uses, has used, or is eligible to use alcohol and other drug services. It includes those people who are refused services or who refuse services. It also includes family, friends and significant others of people who use services, regardless of whether or not they directly use these services themselves. People affected by AOD policy and laws are also considered consumers.[1]

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

SERVICE USER

A service user is a person who uses or has used alcohol and other drug services.

CLIENT

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

FAMILY MEMBER

The word 'family' or 'family member' or 'significant other' is used to describe parents, children, siblings, partners or anyone else affected by a another's substance use. For every person who experiences problematic alcohol or other drug use, there are at least four others who may be affected by their behaviour.[2]

Family members are considered consumers. If a person is in treatment, their family can also be considered service users. If a family member receives treatment (e.g. counselling) from a service, they are also a client. (See also *Family participation* on page 32.)

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.[3]

Consumer participation in the alcohol and other drug sector consists of including consumers (as defined above) in the decision making processes around:

- their own treatment
- service planning, development, delivery and evaluation
- AOD policy
- AOD research
- education and training of AOD professionals.

SERVICE USER PARTICIPATION

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

REPRESENTATIVE

A representative is a consumer who is nominated by and accountable to an organisation of consumers. The term 'representative' is linked to democracy. The representative represents the formal views of a particular group and reports back to that group.[4]

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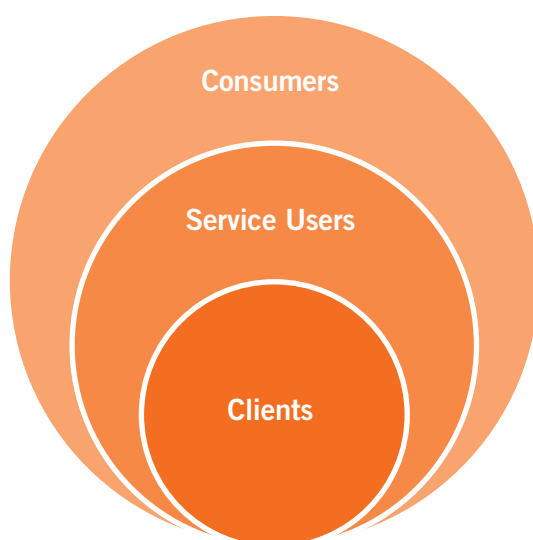

Figure 1: Relationship between consumers, service users and clients

TAB 1

BACKGROUND

HISTORY

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

As early as the late 1800s, women, who came to be known as suffragettes, began their self led campaign to gain the vote. Women all over the western world decided that they would have their say in electing governments that made decisions that affected their lives. This was followed in the 1960s and 70s with the black civil rights movement, the anti-Vietnam protests, gay rights and women's movements.[5] All of these campaigns were led by the people who would be most affected by the changes they sought.

The 60s and 70s also saw the emergence of citizen participation in housing developments, particularly those that affected impoverished communities.[6] The US introduced legislation that required 'maximum feasible participation of the poor' in Department of Housing and Urban Development programs. Closer to home in Sydney, Resident Action Groups were formed in response to proposed housing development projects.[7] Third world countries also benefitted from a shift in thinking, from centralised control of projects to an inclusion of local knowledge in the planning process.[8]

This movement of people demanding to have a say in the things that affect them began in the health sector at around the same time. In the late 1960s, the US passed a law stating that agencies, including mental health centres, should have advisory councils that included consumer representatives.[9] In 1978, the World Health Organization declared that: "People have the right and duty to participate individually and collectively in the planning and implementation of their health care."[10] More locally, the Whitlam government in 1973 launched its Community Health Program with community health centres controlled by the 'local community'.[11] The western world was beginning to recognise that the way to have the best services and improve health outcomes was to seek the input of people using the services.

> "PEOPLE HAVE THE RIGHT AND DUTY TO PARTICIPATE INDIVIDUALLY AND COLLECTIVELY IN THE PLANNING AND IMPLEMENTATION OF THEIR HEALTH CARE."[10]

In Australia in 1985, after a delegation of community representatives presented a submission to the Commonwealth Minister for Health, the Consumers' Health Forum was set up. The 1993 National Health Strategy 'recognised the importance of health consumers being more actively involved in their own health care' as well as 'having a broader role in health service development'.[12] In 1995, after a study found that 8% of hospital admissions experienced an adverse event which could have been avoided, a taskforce for quality control was formed. This led to the formation of the Consumer Focus Collaboration in 1997.[13] This national body, made up of consumers and professionals, is responsible for strengthening consumer input in all aspects of health care.[14] The Health Issues Centre, operating in Victoria has fulfilled a similar role since 1985.[15]

Consumer participation in the mental health and alcohol and other drug sectors occurred very early with self help groups.[16] Alcoholics Anonymous began in the US in the 1930s and there are now estimated to be 18,000 members in Australia.[17] Similarly, Grow, a mutual help twelve-step group for those affected by mental health issues, began in 1957 in Australia and is still thriving today.[18]

More formal participation in mental health services began as a response to pervasive negative experiences of the psychiatric system. The consumer body Victorian Mental Illness Awareness Council (VMIAC) was established in 1982 and funded in 1988. The landmark Understanding and Involvement research project conducted by VMIAC in the early 90s was an evaluation of inpatient treatment practices in a Royal Park psychiatric ward. The study included equal input from consumers and staff and eventually led to the Victorian Government funding consumer consultants in all area mental health services in Victoria.[19] Nationally, federal health ministers endorsed the National Mental Health Statement of Rights and Responsibilities (1991). These rights included 'participation in decision making regarding the development of mental health policy, provision of mental health care and representation of mental health consumer interests'.[20]

The Burdekin Report (1993), a damning national inquiry into the human rights of people with mental illness, was also fundamental in the development of mental health consumer participation. Possibly for the first time, individual experiential accounts were treated as fact, worthy of recording along with the rest of the evidence.[21] The first National Mental Health Strategy (also 1993) had a strong emphasis on consumer participation and led to the development of the National Community Advisory Group on Mental Health (and similar state groups) which reported directly to the Commonwealth Minister for Health. Consumer participation in mental health had become firmly established, although it still had a long way to go.

The AOD sector is perhaps the last bastion of health care to include formal consumer participation. After the emergence of self help groups came the drug user groups. The Australian Intravenous League (AIVL) and its Victorian counterpart Harm Reduction Victoria (formerly VIVAIDS) were formed in the late 80s in response to an increased awareness of HIV/AIDS and received official funding ten years later.[22] These advocacy bodies are peer based organisations that seek to protect the rights and the health of illicit substance users. AIVL recently conducted a large research project into current consumer participation in AOD treatment services in Australia (see *Consumer involvement in research, Control level* on page 101 for further explanation of this project). Consumer participation in the AOD sector began to appear in policy documents in the late nineties and in 2000, APSU received a small amount of funding to increase consumer participation across the Victorian AOD sector.

CONSUMER PARTICIPATION IN THE ALCOHOL AND OTHER DRUG SECTOR

Participation as a right

Consumer participation is an ethical and democratic right.[23] We live in a democracy where we are entitled to vote, however, this in itself is not enough. As citizens we need to have a say by actively participating in the policies and processes that affect the most important things in our lives such as housing, education, health care and employment. All of us need to be given a choice about voicing our opinion on decisions that are made, especially if these decisions directly impact on us and the way we live. This is particularly important for people who use alcohol and other drug services, as their voices are rarely heard in any other political arena.

Participation as accountability

Consumer participation ensures public accountability.[24] With no input from service users, regardless of evaluation or accreditation, there is no knowing if the consumer is satisfied with the service provided.

Participation as policy

Despite lagging behind other health and community service sectors such as mental health, housing and disability services, AOD consumer participation has recently become embedded in sector policy.

Victorian AOD policy is now being framed in terms of having a 'client centred' or 'client focused' service system. *Shaping the future: The Victorian AOD Quality Framework* states: "…a client-centred system has been defined as one that meaningfully engages clients in planning, implementation, delivery and evaluation of interventions and services."[25]

In addition, the Victorian Government's *A new blueprint for alcohol and other drug treatment services 2009-2013*[26] discusses two service principles, one of which is to be 'client centred'. In order to achieve this key action areas include: "Building stronger client and family involvement in service planning and development".[27]

The Victorian Dual Diagnosis Initiative includes service development outcomes and in particular, service development outcome five requires that "consumers and carers are involved in the planning and evaluation of service responses" at mental health and AOD agencies.[28]

Consumer participation is also a feature of quality assurance/accreditation tools for AOD services. For example, there are two core standards in Quality Improvement and Community Services Accreditation (QICSA) relating solely to service user rights and complaints and input into review and planning.

Lastly, the Victorian Alcohol and Drug Association (VAADA) has been funded by the Victorian Department of Health (DH) for a two year sector development project that includes 'strengthening client and family input into service planning and development' as one of its main objectives.[29]

There is no escaping it; consumer participation is a requirement for all publicly funded alcohol and other drug services.

Participation as a prospect

While consumer participation has become firmly entrenched in Victorian AOD policy, there has been no development of a policy framework for its implementation. Nor has there been an allocation of resources for its accomplishment. Current policy documents and accreditation processes do not indicate required outcomes or minimum standards for consumer participation.

APSU endorses the recommendations made by AIVL and Anglicare (Tasmania)[30] that:

- Principles of consumer participation and outcome indicators be incorporated into national and state/territory drug strategies
- Frameworks be developed for the implementation of consumer participation in state and territory AOD sectors which include outcome indicators and systematic evaluation mechanisms
- Adequate resources are provided for the implementation of consumer participation including the training of staff and consumers
- Service provider funding agreements include key performance indicators for consumer participation

Participation as a process

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

APSU acknowledges that without adequate support for consumer participation, such as mentioned in the recommendations above, AOD agencies may find it difficult to meaningfully engage their consumers, especially at medium to high levels (see *Levels of participation* on page 24). However, participation is a process and organisations can aim to increase consumer participation gradually and sustainably over a period of time.

The *Shaping the future* quality framework does give some guidance on what is currently expected of agencies by stating: "As part of continuous quality review mechanisms, agencies are expected to have systems that solicit and make appropriate use of client feedback, suggestions and complaints. Agencies are also encouraged to include clients and clients' significant others in agency review and planning activities where possible".[31]

The framework also states that practical efforts by programs to encourage responsiveness to consumers may be further guided by the following actions:

- The active and independent participation of service users in decisions about their own care and treatment is encouraged and enabled.

- Service users are fully informed about service options and encouraged to provide feedback and make complaints about the quality of services at any time, without prejudice or obstruction.

- Service users have access to independent complaints mechanisms that meet the Australian Standard AS ISO 10002-2006: Customer satisfaction – Guidelines for complaints handling in organisations.

- Service users, their families, carers and friends are encouraged and assisted to participate in the planning, delivery and evaluation of services.

- Programs and services systematically plan and implement service user surveys or other mechanisms, analysing these and developing strategies to address service user concerns.

- Services develop and implement a comprehensive set of policies, procedures and practices that support consumer involvement.[32]

Participation as a possibility

The AOD sector, despite having little practical direction and minimal resources, has shown a remarkable ability, in its development of consumer participation activities, to adapt to new requirements and approaches in order to deliver the best possible services to the people it serves.

Most services, whether they realise it or not, are currently practicing consumer participation strategies at some level. AOD treatment services have 'individual treatment plans' in which a client has a say in their own treatment. This is participation. Suggestion boxes in the waiting room, exit surveys and complaints systems are all consumer participation strategies. Many services employ ex-users as staff and this adds a consumer voice, albeit in an indirect way as workers are not often service users of the services they deliver.

Perhaps the most informative research into consumer participation in the AOD sector is the Australian Injecting and Illicit Drug Users Leagues (AIVL) Treatment Service User (TSU) project.[33,34,35] The project involved interviews with service providers from 64 services in NSW, WA and Victoria as well as 179 service users from 14 of those services.

The project found that most services surveyed had implemented some type of consumer participation activity, with lower level activities such as complaints processes (95%), suggestion boxes (70%) and surveys (64%) being the most common.[36] Higher level activities such as service users being involved in staff selection (10%) or as members of decision making committees (20%) were less common but present at some services nonetheless.[37]

The Victorian Alcohol and Drug Association (VAADA) found similar results when 61 agencies responded to its sector development survey. Over half of the 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.[38]

EVIDENCE

The Consumer Focus Collaboration has played an important role in consumer participation in health service planning and delivery at a national level since 1997. The Collaboration states that:[39]

- Active consumer participation in decision making in individual care leads to improvements in health care.

- Access to quality information facilitates decision-making and supports an active role for consumers in managing their own health.

- Active consumer participation leads to more accessible and effective health services.

- Effective consumer participation in quality improvement and service development activities in health services is achieved through a range of methods.

- Effective consumer participation uses methods that facilitate participation by those traditionally marginalised by mainstream health services.

- Active involvement of consumers at all levels of the development, implementation and evaluation of health strategies and programs is integral to their success.

The first two statements are the most supported by solid evidence.[40,41,42] Unfortunately, a lack of research in the area of consumer participation has led to a dearth of quantitative support for the remaining four Consumer Focus Collaboration statements. For instance, a review of the literature shows that although there is evidence that consumer input leads to changes in health service delivery, there is no body of evidence recording the effects of these changes.[43]

However, while randomised controlled trials are seen as the 'gold standard', we must not ignore other types of evidence nor refuse to change our practices until quantitative data is available. Qualitative research including anecdotal, expert and experiential evidence is also valid[44] and many of the advances in society would not have occurred without it.

Qualitative data supporting the benefits of consumer participation in health, mental health, homelessness services and the alcohol and other drug sector exists in the form of participatory research results, case studies and anecdotal accounts.[45,46] APSU itself, after working for a number of years in this area, has seen some of these benefits first hand.

BENEFITS

Much of the material below is adapted from the *Consumer Participation Resource Kit for housing and homelessness assistance services*.[47] Quotes unless otherwise stated come from the service user, family or provider focus groups or consultations conducted by APSU in the development of this handbook.

Benefits to organisations

- Consumers who feel they have a say are more likely to be positive about new proposals and strategies or changes to existing services if they are involved in the planning process. A feeling of ownership creates greater cooperation between the consumer and the service provider.

- Consumers are a (largely) untapped resource who are able to contribute to the growth of an organisation by providing feedback on programs, as well as offer solutions or answers to problems.

- Consumers may develop a better understanding about the connection between funding and services and may be less likely to express resentment and suspicion of how resources are applied.

- Trust is built between service users and staff.

"IT'S THE REALISATION THAT THE KNOWLEDGE YOU HAVE IS USEFUL… THAT YOU HAVEN'T JUST WASTED 10-20 YEARS OF YOUR LIFE ON DRUGS. YOU'VE ACTUALLY HAD VALUABLE EXPERIENCES THAT CAN BE USED FOR SOMETHING ELSE" – SERVICE USER

- As services improve through the use of consumer participation, staff experience greater job satisfaction.

Benefits to consumers

A better service system

- Higher quality services that are more responsive to consumer needs.

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

- Clients learn the value of peer support.

Empowerment and psychological wellbeing

- As service users engage in the participation process they are more able to express their dissatisfaction with services and to offer solutions or ideas for improvement.

- Disengagement from a particular service is less likely if a service user is given the chance to voice concerns.

- Listening to and valuing a person's experiences and knowledge promotes self-esteem. This is a particularly positive outcome for a person who uses AOD services and may be carrying the shame and stigma of their drug use.

- Participation changes a person's position from that of always needing help to being able to contribute and help others.

- A sense of empowerment contributes to the person's own recovery process.[48] In fact, the very act of participating improves recovery outcomes.

Skills and confidence

- Involvement and participation connects people. It provides support and promotes networking and friendship among peers, workers and policy makers.

- Service users may gain skills in areas such as how to run meetings, communicate ideas, make decisions, deal with conflict and gain support for a cause. These skills can be transferred to a person's wider life and may ultimately lead to employment.

"I go from being the hopeless drug addict to being more useful to myself, having more respect for myself" – Service user

The wider community

Consumer participation in publically funded organisations provides opportunities for participation in democratic decision making. This can build the capacity of service users to engage as active citizens in other arenas.

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

BARRIERS

Attitudes of service providers

'Us and them'

One of the biggest barriers to consumer participation in any field is the 'us and them mentality' held by workers, e.g. 'we are the workers and they are the clients and we know what is best for them'. This divide between 'professional' and 'client' is artificial and unhelpful.[49] Professionals take on a role when they are at work, the role of the expert, the helper, the fixer. This role is encouraged by the people who come to them for help and the very nature of the therapeutic services provided. The professional hat gives people a sense of power and a sense of being useful and able to make intelligent and informed contributions. It can also offer some protection against personal or professional insecurities.

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

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

Fear

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

"The fear factor is the elephant in the room. Professionals are worried about their turf" – Service provider

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

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

"We get requests from consumers to stay longer than ten days [in treatment] but we are unable to achieve this as we would not be able to meet our targets. This is difficult" –- Service provider

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

> ## "PEOPLE ARE AT MANAGEMENT LEVEL AND AT TIMES I FEEL LIKE A BIT OF A KID" – SERVICE USER

Belief

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

Attitudes of consumers

'Us and them'

Consumers may also perpetuate the 'us and them' stereotype.

Fear

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

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

Belief

Consumers may believe they have nothing to contribute or that it is too difficult to contribute in the types of forums offered. Others believe that it is 'not their place' to get involved or that they 'just want treatment', they don't want to be part of the decision making process.[50]

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

Discussion on attitudes

The AIVL Treatment Service User (TSU) project[51] researched the attitudes of both service providers and service users towards consumer participation. Providers' and service users' views were remarkably similar in many aspects. Similar views stated that 'service quality would be improved if clients' opinions about services were included' (84% and 89% respectively), that 'client representatives should be included on committees that decide how services should be run' (72% and 87%) and that 'services should hold open meetings to get clients' views on how the service should be run' (79% and 85%). This demonstrates overwhelming support for the principle of consumer participation from both service providers and service users of the AOD service sector. Both providers and service users were more willing to be involved in lower level activities than higher levels. (See *Levels of participation* on page 24)

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

Overall, the TSU project demonstrated that 'consumers and providers of Australian drug treatment services were strongly in favour of incorporating consumers' views into the process of service planning and delivery'.[52]

Training

Most service providers have not been trained in consumer participation. There are many and varied methods of participation as well as ways of addressing barriers and increasing the likelihood of meaningful participation.

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

APSU conducts training in consumer participation for both service providers and service users.

Even with appropriate training it may still be difficult to know where to start. This handbook includes a section on how organisations can get started on increasing their consumer participation. (See *Part two: A plan for organisations* beginning on page 43)

Resources

Service providers by and large do not have the time or money to undertake consumer participation projects. AOD services have not been funded for consumer participation (except occasionally for one off projects).

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

Confidentiality and privacy

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

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

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

LEVELS OF PARTICIPATION

There are many models that describe community or consumer participation.[53,54] These models are useful for understanding the levels of power that consumers may have in different consumer participation activities. It is important to note that all levels of participation are necessary and valid.

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

Table 1: Ladder of participation[55]

COMPLEXITIES AND LIMITATIONS OF THE LADDER

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

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

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

DOMAINS OF PARTICIPATION

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

Figure 2: Domains of participation

Participation in any of these domains may be at low to high levels. For example, policy makers could invite service users to respond to a survey (consultation) about a proposed policy or to be part of the team drafting the policy (partnership). This handbook focuses mainly on involving consumers in organisational decision making; however, there are sections on consumers in education and training (page 90), policy development (page 94) and research (page 98) towards the end of the handbook.

MEANINGFUL PARTICIPATION

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

- Being clear about your organisation's capacity to involve service users and to respond to service user concerns.

- Being careful not to promise what you can't deliver.

- Consumer participation is only productive if it is supported by management at all levels.

- Effective consumer participation means that your organisation must be prepared to listen to feedback, make decisions and accept any changes.

- Enhanced consumer participation may mean that conflicts emerge and will need to be managed. This is okay and is likely to lead to better quality service and improved outcomes in the long term.

- Partnerships with service users are based on dialogue and trust. Trust is built by transparency and consistency.

- Service users are engaged early in the process - even in the process of deciding how your organisation will engage service users better.[56]

PRINCIPLES AND PRACTICES[57]

Timeliness

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

Honesty

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

Inclusiveness

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

User friendliness

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

Respectfulness

When consulted, consumers may not respond as desired. While the organisation may be interested in addressing a particular topic, the service user may be far more concerned about giving feedback on another, more pressing matter. Although it can be frustrating not to get the type of feedback you are looking for, see this as an opportunity to demonstrate to service users that you have heard them, rather than an opportunity to explain why you cannot do anything about their concerns. Inform service users of the avenues they can use to pursue other issues and offer assistance. Then return to your agenda.

The Standing Committee on Drug Abuse (SCODA) included the observation that:

"It is often the case in user groups that people need to spend some time complaining about the abuse they have suffered as drug users, and rightly so. When a group survives this, the work can begin – and the experiences and opinions can be used in the planning and development of services".[58]

"IT IS OFTEN THE CASE IN USER GROUPS THAT PEOPLE NEED TO SPEND SOME TIME COMPLAINING ABOUT THE ABUSE THEY HAVE SUFFERED AS DRUG USERS, AND RIGHTLY SO. WHEN A GROUP SURVIVES THIS, THE WORK CAN BEGIN – AND THE EXPERIENCES AND OPINIONS CAN BE USED IN THE PLANNING AND DEVELOPMENT OF SERVICES"

Remuneration

In most cases, consumer participants should be remunerated. Many consumers participate for free but it is important to recognise that a service user's time and input should be valued just like that of a professional. Financial remuneration based on the rate for mental health participants is $46 for two hours or part thereof for participation in meetings, forums, focus groups and committees. This money assists with transport and out of pocket meal expenses. At APSU, consumer participants are paid a flat $40.00 per meeting or focus group. It is important to plan for consumer participation expenses when creating budgets for new projects.

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

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

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

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

Some service providers, hesitant about giving clients cash payments, use vouchers as a means of remuneration. This method of payment is considered by many service users to be demeaning, as it implies that consumers should not have the same freedom of choice in spending money as the rest of society. Professionals would not like to be paid in this fashion.

Training and support for consumers

For consumers to become involved in higher level participation roles, such as joining committees, facilitating service user groups, and contributing to staff selection, it is desirable they receive proper training and support. APSU offers a series of four consumer-based workshops called 'Experts by experience' which cover topics such as the AOD service system, AOD policy and advocacy, how to participate in meetings and self care for consumer participants. (Refer to the APSU website for the FIT Peer Model Training http://www.apsuonline.org.au/index.php?page=peer-helper for more information.) Other organisational based training may be relevant to the role performed. It may be possible to consider current staff training and induction processes and adapt them for consumer roles.

Consumer participants in medium to high level activities should be offered supervision as extra support (see *Levels of participation* on page 24). Supervision is best done independently of the relevent organisation for two reasons – organisations are not experts at consumer participation experiences and it may not be appropriate or easy for participants to discuss any concerns that arise with service staff.

APSU is able to provide training and support for consumer participants as well as opportunities to connect with other consumers in participation roles.

Other Issues to consider

Responder bias

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

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

Bias of paid consumer representatives

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

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

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

EVALUATION

WADSWORTH'S ACTION EVALUATION RESEARCH PROCESS

The simplicity of the Wadsworth's Action Evaluation Research Process (1997) makes it an invaluable model upon which to conduct program evaluation. This tool will be used as the basis for this section of the handbook.

Associate Professor Yoland Wadsworth, a research sociologist, said: "We must effectively point evaluation in the direction of always seeking to identify 'who' or 'what' it is all for"[59] and this can be applied to consumer participation where the process of identifying 'who' or 'what' the activity relates to, is valuable for three reasons. Firstly, it establishes the need to measure expectation against what actually happens; secondly, it provides the information needed to improve or adjust project aims; and thirdly, it potentially provides a valuable vehicle for further consumer involvement.

Evaluation begins at the inception of a project, with planning for evaluation a part of the overall plan of the project. A consumer participation project may start with consumer observation of the discrepancy (large or small) between what is expected and what is experienced.[60] For example, it may be deemed a problem that consumers are not involved in the selection of staff in an organisation that reportedly values consumer participation.

Indicators

Outcomes are also known as indicators. These are used to assess whether an organisation is achieving the goals of the project.[61] For example, a consumer who has been selected to participate in staff recruitment may be set the following indicators:

- the consumer will actively contribute to the discussion during the short-listing of applicants

- the consumer will participate in the development of questions

- the consumer will directly question the interviewee

- the consumer will participate in post interview discussion

By establishing these indicators beforehand, service providers are not only clear about what is expected of participants, but have clear expectations that both parties can review and assess. Needless to say, it is an advantage if consumers are involved in the establishment of these indicators. This allows for greater accountability and interest in the project on the part of the consumer. For the service provider, it achieves the goal of thinking 'out' or finding out what others think.[62]

Fieldwork

In order to find out what consumers and colleagues think of a project, service providers need to develop methods of 'immersing in their world'.[63] Establishing an understanding as a result of observing, reading, listening and participating is just as important as ensuring that the collaborative process involves all parties who will be affected by the project outcomes.[64] This means that conclusions are based upon what happens and not a single individual's idea of what occurred.

Tools

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

Focus groups

A group discussion held a month after the conclusion of a project gives more time for consumers to reflect on the effectiveness of their participation, and thereby give a more meaningful critique. People may be overly positive when filling out evaluation forms as they don't want to offend, so it is important to prepare and establish the rules of engagement beforehand. Develop broad questions that will give people the space and understanding to raise an unexpected topic or question. (See page 61 for more on focus groups)

Feedback forms

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

Journal

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

Reports or reflective evaluations

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

Feedback to consumers and staff

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

Planning

Work practices and policies can now be improved or changed accordingly, and the process can inform future projects. According to Wadsworth, an evaluation involves researching other people's ideas of things.[65] Time is taken to consider everyone's point of view and reflect upon and think about the changes that this will catalyse.[66] The best evaluation provides a lead on where to go next, whether it is to do what was intended in the first place or to address a problem by acting on a solution.[67]
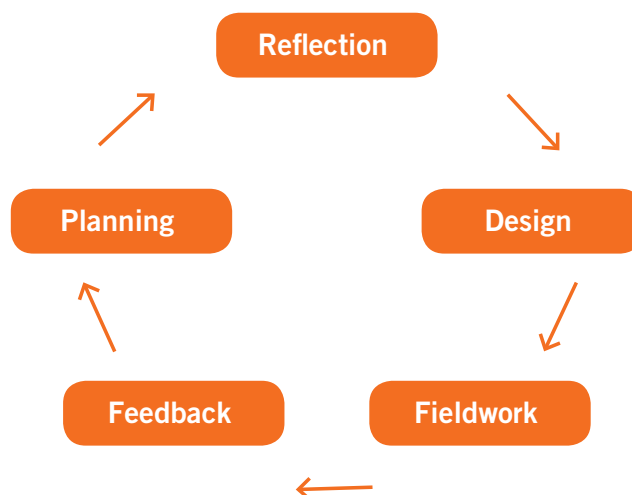

Figure 3: The Action Evaluation Research Process[68]

FAMILY PARTICIPATION

"My son had a serious accident and I was told that he might lose his leg because he was a drug user and the doctors felt that they couldn't put his leg in a non weight bearing cast… They didn't think he was capable of using this… [and] they were going to amputate his leg. So I went to the chair of the hospital board and quoted their charter to them about the rights of the individual and it was all changed and I went home with my son after the operation with the non weight bearing cast. Now my son is in recovery and living a valid and responsible life. In this case I was able to have input, but many families don't and they are excluded…" – Family member

"[THE WORD CARER] PUTS PEOPLE INTO THE TRIANGLE OF RESCUER, PERSECUTOR OR VICTIM. 'I AM IN CONTROL OF THIS PERSON' AND 'I CAN'T DO THIS AS I HAVE TO STAY HOME AND CARE'. I SHY AWAY FROM THIS ROLE" - FAMILY MEMBER

Family participation in alcohol and other drug services has just as strong a presence in Victorian policy as service user participation. Like service user participation there are difficulties in convincing service providers to make this a part of service provision, policy development, education, training and research, due to the fact that, on the whole, family is not usually involved in direct service provision. AOD services predominantly focus on the individual and have difficulty with treating their clients as part of a wider community.

Family participation doesn't necessitate that AOD service users are in contact with their family or consider family members as significant others. Nor does it mean that the sector should bring family and service users together in order to engage participants. Family participation can occur separately from service user participation. Stakeholders with different perspectives and experiences have a much greater power to influence policy and improve current practice in the AOD sector. For direction on where to start with family participation use *Part two: A plan for organisations* on page 43.

DEFINING FAMILY

For the purposes of this handbook family can be a spouse, partner, sibling, child or significant other of an AOD service user or consumer. These people may have varying relationships with the person identifying as having an alcohol and other drug issue.

Commonly, family participation is known as carer participation with the term 'carer participation' used in policy and literature. However, the term 'carer' is associated with the intensive care giving of an adult to a child and connotes an identity that is not necessarily desirable to drug users and their family members. 'Carer' assumes there is only one person involved and terms associated with carer participation such as 'carer burden', 'under his/her care' and 'level of caring' have negative connotations and are disparaging for the person being 'cared for'. According to Carers Victoria, this is especially the case for young people whose parents are AOD service users. These young people are staunchly loyal to their family and at the same time fear intervention from government services. They do not choose to be a carer of their parent or sibling[69] and the term 'carer' is not an accurate reflection of their experience.

It makes sense that an individual's AOD use potentially impacts a number of people including friends or work colleagues who are outside the family, marriage or relationship. The word 'carer' fails to capture this experience.[70]

Also, it is arguable whether the term 'carer' is appropriate to the experience of alcohol and other drug use, as the concerns of the family are different from those of people who are caring for a person with a disability or serious mental health issue. People who use alcohol and other drugs are generally more autonomous in terms of physical mobility and independent living skills. The concerns of family members or significant others are mostly about the extent of a loved one's alcohol and drug use, the threat of incarceration or serious health problems, the security of their possessions, the breakdown of relationships and the impact that the alcohol and other drug use has on overall family health and wellbeing.

In addition to this, 'significant others' are people who are affected by an individual's drug use including friends and colleagues.[71] It is more than likely that a friend, colleague or perhaps a manager would not relate to the term 'carer'. In fact, Copello et al refer to family and social networks in their review of family interventions for alcohol and other drug misuse.[72] This broad concept of 'social networks' is almost incompatible with such a limited term as 'carer'. Furthermore, the idea of 'social networks' is one that is fitting with everyday experience as opposed to what conveniently fits with a policy document. Given these differences it seems reasonable to discuss family and significant other involvement as 'family participation' rather than carer participation. It does need to be acknowledged however that some people do identify as carers in existing networks.[73]

FAMILY AS CONSUMERS

As discussed in the *Definitions* section of this handbook, family and significant others are consumers when a significant person in their life is in treatment or they are seeking help for themselves to cope with the effects of alcohol and other drug use of a son, daughter, spouse, partner or friend.[74] For example, family of a young person who uses Recovery Support Services (RSS) at Self Help Addiction Resource Centre (SHARC) may use the various services offered by Family Drug Help (FDH), also a program at SHARC. The provision of AOD services and AOD policy affects family just as it does the people who use substances problematically.

Family participation confused with treatment

Whilst consulting for this project it has been made obvious the lack of distinction between family in treatment and family participation. Often participation is confused with treatment or setting up support groups and training for family. This type of engagement is a means to laying the foundation for family participation, but is not considered participation. As stated in the definitions earlier in this handbook, participation may be the involvement of consumers in decision making in treatment but it is also much more. Family involvement in decision making around service provision, policy development, education and training and research is very different from receiving treatment. This distinction is necessary when developing AOD policy and training.

> "FAMILY IS A HIGHLY CONTESTED WORD AS IT IS DEFINED IN TERMS OF THE INDIVIDUAL EXPERIENCE OF FAMILY. PEOPLE NOMINATE PEOPLE AND SAY THAT THEY ARE THEIR MOTHER BUT THEY ARE NOT THEIR MOTHER" – SERVICE PROVIDER

Family participation and consumer participation

Most of the literature available on consumer participation involving family is about family participation in mental health services. Usually family participation (defined as carer participation) is coupled with service user participation (defined as consumer participation). This is understandable as there are similar considerations and strategies required for the participation for family.[75] Like service users, innovative strategies are required for recruitment of family. The degree of innovation will reflect the extent of contact that AOD services have with family. Services need to be active in recruiting family, making it known that they are always welcome to contribute and ensuring that there is a point of contact and opportunities for family who may be interested in contributing.[76] Change in the culture of the organisation is required before services can effectively include family in consultation and decision making.[77] Stated in the Victorian Government's 'Doing with us not for us' (2005), is the principle of health services and government departments building ways of working with families.[78] The Commonwealth Government also acknowledges that equipping service users with training, knowledge and skills will enable them to participate in decision making and that support and recognition of the roles undertaken by family should be mandatory.[79]

In the focus group for family conducted in the development of this handbook, participants lamented the general lack of information provided by services. This led to a feeling of disenfranchisement from the AOD treatment service their relative or partner was attending.[80] The importance of information is highlighted in *'Extending the boundaries of consumer participation'*, Brooke and Berends' evaluative research into the involvement of significant others.[81] Moreover, Orford states that informational support is what people find most useful in times of stress.[82]

"I have seen carers without knowledge get squashed like bugs" – Service provider

FAMILY PARTICIPATION

A drawback of combining family participation with service user participation is that the differences between the two groups are neglected. Family participation warrants separate consideration because of the heterogeneous nature of family and the relationships family may have with AOD service users.

Family can be people one lives with or someone who looks out for another.[83] Recruiting processes need to honour these complexities as well as the history and current practice of family involvement in AOD service provision. Focus group participants described experiences where their treatment was tantamount to that of an annoying telemarketer, and similar experiences were described by participants in the Brooke and Berends study.[84]

"People have a lot of pain around the term 'family'. It is a term with a lot baggage" – Service provider

"Their rights [service users] are number one but it was like we had no rights. You get a sense like, 'What do you want?'" – Family member

"I find it interesting that a person is given a form where they can nominate a contact, but when you ring you are treated like you are a waste of time… as they won't even tell you whether they have left [treatment] or not" – Family member

Barriers to family participation

Family unwanted

The lack of consciousness or awareness about involving family was captured by the consultation process, despite the fact that family in treatment is a key feature of the Victorian Government's 'New Blueprint for AOD Treatment Services 2009-2013'.[85] This may stem from the belief that families are the main source of problems experienced by service users and so need to be contained.

On the whole the family focus group participants perceived themselves as insignificant to service providers. The particular injustice in relation to this experience is that families have a substantial increase in responsibility when their loved one is in need of help. Because of the deinstitutionalisation of mental health services, families play an increasingly important support role in facilitating the provision of housing, finances, and management of day to day affairs.[86] This immense responsibility is also often the case with AOD service users as a result of inadequate funding for the sector.

"The attitude is that families are fucked up and let's keep them away from service users" – Service provider

Waiting times

Waiting times for services are a barrier to family participation. Family commented that this affected them on an emotional level, that they found the process exhausting and frustrating.

The stress placed on the participants of the family focus group when their loved one was unable to get into treatment was salient, and impacted on their capacity to connect with AOD services.

"It needs to be recognised that people have periods of chaotic use and other times when it is well reigned in. When things are out of control is when family members are affected. They have a sense of exhaustion. Perhaps in times of quiet, family are better able to participate" – Service provider

"If you've got a physical illness then you go into triage, but if you have an illness like an addiction then you can wait. Your family can look after you but when your son or daughter comes in [for treatment] they don't want anything to do with the family. They use you to fill in the gaps but when [your child] gets into detox, you don't matter" – Family member

Information

Relevant and timely information is pertinent to family participation. Without the right kind of information and a sense of involvement, families experience disconnection from AOD services. In actuality, family are often interested in the day to day workings of services and would feel more confident if program information was made available to them.

Organisational culture

Family participation is dependent on the organisational ability to engage them. Undoubtedly, organisational readiness is a key component of any consumer participation.[87] This includes providing a point of contact for family and clear information about service functions and limitations. If there is the means for further involvement, families need to be invited to participate. Organisational policy and associated protocol needs to be developed and reviewed regularly. Effective changes need to be supported by management and resourced appropriately.[88]

Staff training

Staff training is a means of embedding the practice of consumer participation and thereby shifting organisational culture so it is ready to incorporate family participation as a part of current work practice. In a 2009 discussion paper compiled by Family Drug Support (NSW), it is recommended that agencies conduct an audit of workers' skills pertaining to working with families and develop suitable training programs. The same process can be applied to family participation.

Confidentiality

One of the main concerns raised by family during the family focus group was confidentiality. Agency practices varied depending on whether the service was private or government run. Clearly organisational policy is designed to protect the privacy of their service users, but this need not be a barrier to family participation. Family can contribute their ideas to service provision or policy without having to compromise confidentiality. Engaging family from the outset will ensure that they are aware of the information they are able to access.

Organisational resources

Given that the AOD sector is underfunded, resources are a key consideration for institutionalising any new practices. As one of our consultant participants pointed out, it is not so much skills but whether there is the mentoring and support available to alcohol and other drug workers to implement a new practice. Much is expected from AOD workers and their workloads should be kept in perspective. It is better to keep deadlines and targets achievable rather than overwhelmingly impossible and outside the realm of current capacity.

Capacity of family

Family may not be able to attend committee meetings or focus groups, not only because of work and other commitments, but because the management of a crisis situation in relation to a loved one's alcohol and other drug use is time consuming and emotionally draining. In the mental health sector, it has been identified that a person with a mental health issue is often dependent on a significant other who is female and may themselves be vulnerable, often with reduced social and economic power.[89] This experience was also noted by members of the focus groups.[90]

"People are busy. Families are busy souls" – Service provider

Stigma

Alcohol and other drug dependence (especially the use of illicit drugs) is not generally tolerated in our community. As a result family living with problematic use do not readily identify their needs. Family desire anonymity and having contact with people who have similar experiences. Focus group participants described the advantage of joining support groups as being with people of like experience.[91]

The Bouverie Centre acknowledges the importance of 'critical mass' and that people need a group to belong to, a feeling that they are part of something, rather than dealing with AOD issues on their own. Isolation was viewed as a barrier to successful family participation.[92]

"[Support group] involvement gives them a purpose and sense of meaning. They say in groups this is the only place they can come and be honest. Coming here is like a pressure cooker release. They can see the value of sharing experiences and being in a safe place. For example a family member brought a cake celebrating the fact that her son did not go to jail" – Service provider

Prohibition

Families and Friends for Drug Law Reform cite prohibition as a barrier for families, and one that adds to the stigma and shame commonly felt by people.[93] Family may speak of their loved one's death as a car accident rather than a drug overdose. This is a result of the stigma that prohibition produces. According to 'Modernising Australia's drug policy' by Moore and Wodak (2002), prohibition leads to the punishment of behaviours that are a result of social and health issues.[94] It is fair to say that families are also punished as a result of their family member's AOD use.

Language

The AOD sector is filled with jargon and acronyms that may intimidate and exclude people whose perspectives and ideas are important to service provision and policy. It is vital to participation that language is easily understandable, that the use of acronyms is sparing and that a clear explanation of technical information such as drug treatment names and medical terms etc. is made available.

Family participation in action

Family participation requires practice and service providers need to recognise and address potential barriers to involvement. Follow the suggestions outlined in *Part two: A plan for organisations* on page 43 and be mindful of the differences involved when working with families and AOD service users when designing and planning new projects.

For examples of family participation see *Involving family members in the evaluation of residential rehabilitation services* on page 61, *Peer volunteers at SHARC's Family Drug Help* on page 73, *Family Drug Support representation on committees* on page 84 and *Family providing the consumer perspective in a guest lecturer capacity* on page 91.

"ALL WRITERS CAN IMPROVE, SO THE PUBLIC LANGUAGE CAN IMPROVE. IT IS A QUESTION OF CONSCIOUSNESS AND NECESSITY. IF IT IS THE RIGHT OF ALL CITIZENS TO KNOW, IT IS EQUALLY THEIR RIGHT TO BE COMPETENTLY TOLD."[95]

PLANNING FOR DIVERSITY

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

INDIGENOUS AUSTRALIANS

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

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

Barriers can be addressed by both a cultural audit and cultural sensitivity training. An audit tool readily available is the Koori Practice Checklist which can be downloaded from the Ngwala Willumbong Cooperative Ltd website.[96] The checklist evaluates policies and practices and recommends working with a specialist Indigenous AOD agency when conducting an audit. Cultural sensitivity training provides staff with knowledge and awareness of Aboriginal cultures and heritage, as well as ways of working more effectively with Indigenous service users.

The contribution of ideas and opinions by Indigenous consumers is vital in building a service model that is appropriate and respectful for all people with alcohol and other drug issues. The processes outlined in this handbook require time, planning and support from both executive and staff, and specialised Aboriginal AOD services must be consulted in order to make service delivery more meaningful. This is especially pertinent given the Closing the Gap campaign, a response from the Federal Government to achieve health equality for Aboriginal and Torres Strait Islander people within 25 years. One of the key commitments in this campaign is Government working to ensure full cooperation with Indigenous people and their representative bodies in all aspects of addressing their health needs.[97]

See also the *Resources* section on page 106.

PEOPLE FROM CULTURALLY AND LINGUISTICALLY DIVERSE (CALD) BACKGROUNDS

The Centre for Culture, Ethnicity and Health states: "Taking the time to consult with CALD communities and understanding their needs is essential for working effectively with them".[98]

One of the methods used to estimate the use of AOD services by people from CALD communities is the minimum data set (MDS). In NSW, the proportion of service users in 2004–05 born in a non English speaking country was around six per cent.[99] However, the proportion of people born in a non English speaking country in the general population was seventeen per cent. This shows a disproportionately low use of services by these communities.

One explanation for this disparity could be that CALD communities use less alcohol and other drugs and therefore require less service use. Although there is no comprehensive literature on drug use amongst CALD communities, there is an indication, obtained from national census data that there is less use of alcohol, tobacco and illicit drugs.[100,101] However some sources disagree, suggesting there is more substance use in these communities.[102] Whatever the real figures, the conservatively low drug use data is still not enough to account for the low use of services.[103]

There are many cultural factors that may explain the lack of engagement of CALD communities with AOD services and these include:

- lack of awareness of available services or familiarity with 'counselling' type services
- lack of culturally sensitive services
- language
- fear of stigma and ostracism
- fear of persecution (by government authorities)[104]

Consumer participation by CALD communities is most likely at a disadvantage due to language barriers. Health information and treatment options may not be adequately conveyed to CALD service users, which affect their ability to participate in their own treatment as well as offer their involvement at higher levels of participation. Cultural misunderstandings, lack of reciprocal communication with service providers and a lack of understanding about the service sector are other contributing factors. CALD consumers may originate from countries where consumer participation is unheard of or where only positive feedback is permitted.

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

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

The Victorian Department of Health outlines six areas for action to increase the use of health services by people from CALD communities:[105]

1. Understanding clients and their needs.

2. Partnerships with multicultural and ethno-specific agencies.

3. A culturally diverse workforce.

4. Using language services to best effect.

5. Encouraging participation in decision making.

6. Promoting the benefits of a multicultural Victoria.

See also the *Resources* section on page 106.

PEOPLE WHO ARE GAY, LESBIAN, BISEXUAL, TRANSGENDER OR INTERSEX (GLBTI)

GLBTI inclusive practice needs to be considered as part of the other culturally sensitive practices that are outlined in this handbook.[106] As with other communities, it is important that service providers have knowledge of the specific needs of GLBTI people.[107]

Before considering consumer participation with these groups, organisational practice needs to incorporate six recommendations for inclusive practice that are outlined in the Victorian Department of Health's *Well proud: A guide to gay, lesbian, bisexual, transgender and intersex inclusive practice for health and human services.*[108] These are:

1. A welcoming environment.

2. Staff education and training.

3. Staff/client communication that promotes acceptance of sexual orientation, gender orientation and relationship status.

4. Documentation where staff seek consent when recording information and offer reasons why information is needed.

5. Referral and resources where consumers benefit from a database of GLBTI support groups and services.

6. Disclosure and confidentiality where confidentiality statements are developed that are specific to GLBTI and the right not to disclose is respected.

Whilst adapting policies and procedures it may be helpful to collaborate with a specialist GLBTI agency. These are listed in the *Well proud* guide and can also be found at the back of this handbook in the *Resources* section.

See also the *Resources* section on page 107.

PEOPLE WITH A DISABILITY

According to Section 3 of the Disability Act (2006), a disability is:

(a) a sensory, physical or neurological impairment or acquired brain injury or any combination thereof, which –

   (i)   is, or is likely to be, permanent; and

   (ii)   causes a substantially reduced capacity in at least one of the areas of self care, self management, mobility or communication; and

   (iii) requires significant ongoing or long term episodic support; and

   (iv) is not related to ageing; or

(b) an intellectual disability; or

(c) a developmental delay

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

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

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

See also the *Resources* section on page 107.

AS WITH THE OTHER COMMUNITIES, PLANNING FOR CONSUMER INVOLVEMENT STARTS WITH ORGANISATIONAL POLICY AND PROCEDURE IDENTIFYING CLIENT NEEDS AND MAKING PEOPLE WITH A DISABILITY FEEL WELCOMED AND RESPECTED.

MENTAL HEALTH AND DUAL DIAGNOSIS

The treatment and care of people experiencing mental health issues has now become 'core business' in the alcohol and other drug sector.[109] It is estimated that 75% per cent of people with a substance use problem may also have a mental illness.[110] Consumer participation in the AOD sector inevitably involves people who have what has come to be known as a dual diagnosis or co-occurring disorder.

With the advent of the Victorian Dual Diagnosis Initiative and the federal Improved Services Initiative, many AOD services are becoming dual diagnosis capable. In addition to this, as formal consumer participation in the mental health sector has been established for far longer than in the AOD sector and has been included in the dual diagnosis policy material,[111] there is a new impetus for including service users and their families in decision making processes.

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

The same principles used in consumer participation for people with substance use apply to people experiencing a dual diagnosis (see *Principles and practices* on page 26). However, many people with a diagnosed mental illness may not wish to identify as having a 'drug problem' or may not view their drug use as problematic. Conversely, people with a diagnosed substance use disorder may not be willing to acknowledge their mental health concerns. Moreover, as the AOD sector has in the past referred mental health issues to mental health agencies, AOD service users have been 'trained' or led to believe it is better to keep mental health issues to themselves.

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

APSU can be contacted to recruit consumer participants who identify as having a dual diagnosis.

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

VMIAC can be contacted for recruiting mental health consumer participants
(See *Resources* section on page 106).

TAB 2

MOVING FORWARD

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

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

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

Improve
- Educate staff and recruit interested staff and service users
- Improve, existing activities especially ones that support participation (complaints systems, consumer rights)

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

Recruit
- Recruit and train service users

Figure 4: A plan for organisations

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

AUDIT CURRENT CONSUMER PARTICIPATION

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

Current activities

Complaints system

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

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

See *Complaints process* on page 53 for suggestions on how to improve your complaints system.

Information provision

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

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

See *Information provision* on page 52 for further information.

Suggestion box

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

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

See *Suggestion boxes* on page 54 for more information.

Surveys

- Has/does your organisation conduct surveys, including exit surveys?

- Who designs the surveys?

- Are service users ever involved in designing surveys?

- What happens to the information collected?

- What is the information used for? Is there a policy for this? Is it followed?

- Consider why surveys are conducted. What purpose do they serve?

- Does the survey process improve services for clients?

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

See *Surveys* on page 57 for more information.

Past activities

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

- What consumer participation activities have been undertaken in the past?

- What worked?

- What didn't and why?

- Why did the activity end?

- What barriers were encountered?

- Was there any damage done to the trust relationship? With staff? With clients?

- What needs to be done to address any damage caused by the activity?

- What can be learned from this experience? What can be used in the future?

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

Organisational readiness

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

- Does the organisation have a consumer participation policy? (See page 47)

- Is the board supportive of consumer activities?

- What are staff attitudes towards consumer involvement?

- What current/past experiences, both positive and negative, have influenced these attitudes?

- What resources are available for consumer participation?

- What supports are available for service users involved in participation?

- What are the known barriers to participation that apply to the organisation? (See page 21 and 35)

- What level(s) of participation does the organisation currently offer? (See page 24)

- What level of participation is the organisation comfortable at aiming towards?

IMPROVE EXISTING CONSUMER PARTICIPATION PRACTICES

Once an organisation has established what it is already doing and how well it is going it is time to reflect on how this can be improved.

After having done an audit and deciding what works well and what doesn't, start to plan what action to take to improve existing practices.

Look at the examples of complaints systems (page 53), information provision (page 52), suggestion boxes (page 54), surveys (page 57) and service user groups (page 64) for ideas. An example on page 55 illustrates how an organisation has improved several of its foundational consumer participation practices.

Get others involved

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

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

APSU is experienced in training staff and board members.

Involve service users early

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

APSU provides consumer participation training to service users and is able to provide independent support and mentoring for service users involved at medium to high levels of participation.

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

For more information see *Recruit service users* on page 48.

Make service users aware

It is essential to make clients aware of existing and new participation opportunities, and encourage them to become involved. AIVL consumer participation research demonstrates that service users are often unaware of the participation opportunities available to them. For example, only half of service users knew that their service had a complaints system.[112] The scope and limitations of the activities should also be made clear to service users.

Write a consumer participation policy

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

The policy should be written in plain language in order to be accessible to clients and should be publicised to both staff and clients. See *Appendix 1* on page 109 for an example of a consumer participation policy.

BUILD NEW OPPORTUNITIES FOR CONSUMER PARTICIPATION

Start small

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

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

Involve service users early

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

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

Sustainability

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

RECRUIT SERVICE USERS

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

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

Consent form

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

A consent form may contain:

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

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

APSU membership

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

See *Appendix 2* on page 110 for an example of a combined consent form.

Training and support

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

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

Organisations should also provide adequate support for consumer participants, similar to that of staff supervision, with available resources permitting. APSU can be called upon to provide supervisory support to consumers engaged in participation activities. Outside, independent support for consumers, especially from people who understand what it is like to participate in a consumer role, is immeasurable.

TAB 3

THE EXAMPLES

While theory is necessary to form the basis for good practice, it is always the practice itself that brings a subject to light. For this purpose, APSU has included over 50 examples of consumer participation in the alcohol and other drug sector. The examples have been drawn mainly from activities that APSU has been involved in as well as those of Victorian organisations that responded to an email enquiry.

Several examples were also added from a non-systematic literature search and involve Australian or overseas AOD agencies. In addition, there is one example from a Melbourne housing service.

Part two is arranged in four sections:

• Organisational examples

• Education and training examples

• Policy development examples

• Research examples

These have been referred to as domains of participation (see *Domains of participation* on page 25) Each section discusses the reasoning behind a particular consumer participation activity, its uses and one or two practical examples. The participation activities in each section are arranged from low level to high level participation (see *Levels of participation* on page 24).

It was decided not to deidentitfy the organisations and services named in the examples for two reasons:

• It is difficult to deidentify organisations in such a small sector without losing important relevant information

• APSU hopes that by using the names of organisations, agencies will more easily share their knowledge and experience of consumer participation with each other.

APSU has added comments to each of the examples, both to illustrate certain aspects of applied theory and to indicate areas for enhancement.

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

CONSUMER INVOLVEMENT IN ORGANISATIONS

INFORMATION LEVEL

Giving out information is not participation, as the information flow is one-way. Providing information does not change how services, policy, research, treatment or care are conducted. However, information is often used to support or invite participation. For example, information about how to access a service and what is involved in the care or treatment of a health issue provides necessary information required for an individual to make decisions about their own treatment. Without this information the service user would be less able to make an informed decision about their health care. For this reason, information is usually identified as supporting participation.[113]

Information provision

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

It has been said that 'knowledge is power'. It is important that organisations do not censor any information that is provided. When providing information about treatment options all options should be presented, including those that the organisation may not deliver, treatment where there is little empirical evidence about effectiveness, treatment that has a religious or self help basis or requires private health cover. Organisations should not limit or remove service users' power by making decisions about which information is best for them. This right to receive adequate information on all services and treatments will be a part of the new Victorian AOD Charter. (See the example *Victorian AOD Charter (draft)* on page 53.

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

Services directory for drug and alcohol users

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

Fitzroy Legal Service Services Directory for Drug and Alcohol Users 2007 edition, Fitzroy Legal Services Inc, 2000. Unfortunately the hard copy of the book is currently unavailable but the contents can be downloaded online at: http://www.fitzroy-legal.org.au/cb_pages/about_services_directory.php

Consumer rights

Currently AOD service users have significant privacy rights as well as those provided for under the Equal Opportunity Act and the Victorian Charter of Human Rights and Responsibilities. Furthermore, a Charter of Rights for AOD service users has been developed by APSU and will soon be made available by the Victorian Department of Health. Some organisations have also produced their own statement of client rights. Many agencies make their service users aware of these rights by prominently displaying them or providing pamphlets on the topic (see Moreland Hall's Client Charter in *Appendix 3* on page 111).

Victorian AOD Charter (draft)

As an advocacy service that upholds the rights of people using Victorian AOD services, The Association of Participating Service Users is happy to introduce this Charter of Rights and Responsibilities. The Charter was developed from the knowledge of 160 users of AOD services who participated in focus groups held across Victoria. The making of this Charter, by people who use Victorian AOD services for people who use Victorian AOD services, has endeavoured to follow a democratic process, the implementation of which will contribute greatly to a fairer Victoria. APSU 2007

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

- Be provided a service in a safe environment
- Be provided a service in a fair and non-judgemental manner
- Be provided a service that is friendly and respectful
- Be given adequate information on all available services and treatment
- Participate in all aspects of service provision
- Have information about you kept confidential unless safety to you or others is at risk
- Be provided with timely and effective service that responds to your needs
- Make a complaint and for this to be addressed efficiently
- Be provided culturally sensitive services that take into account your values and beliefs.

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

- Be familiar with your rights and responsibilities as a person using Victorian AOD services
- Contribute to maintaining a safe environment
- Treat others with respect and courtesy
- Participate in the treatment process to the best of your ability
- Follow the organisational complaints process. If you are not satisfied you can make an external complaint to DH or the Health Services Commissioner

UK Drug Service User's Charter of Rights

The Department of Health in the United Kingdom has stated that the Patients Charter is applicable to drug users. Even so, the Standing Conference on Drug Abuse (SCODA) has published the Drug Service User's Charter of Rights to ensure that drug service users are aware of their rights in a treatment setting.[115]

Complaints process

As stated in a previous section, complaints systems are one of the foundations of consumer participation, they are the most basic of feedback mechanisms. An effective complaints process provides the opportunity for consumers to participate at a consultation level.

Service users should be educated about the complaints system, encouraged and, where required, assisted to use it. As most organisations have a complaints policy, it may be the first opportunity for service users to provide feedback. An effectively utilised complaints system can identify a service's weak spots and can be a used as a quality assurance tool. Staff need to be educated about the benefits of service users having their complaints heard. No one likes to be criticised or reprimanded, however, a solution focussed complaints system and culture will ultimately improve morale and open up opportunities for training and support, benefitting both staff and service users. (See also the example *Moreland Hall's new Client Charter and feedback mechanisms on page 56.*)

Verbal complaints treated seriously at a housing service[115]

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

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

CONSULTATION LEVEL

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

Consultation is used to find out what consumers think of something. Consumers may be asked about existing services or facilities, new proposals or how to identify areas for improvement, however, the service remains in control. Consultation can improve services and increase acceptance and consumer confidence in the organisation.[116]

Confidentiality

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

Suggestion boxes

Over two thirds of AOD services surveyed in the AIVL consumer participation research were found to have suggestion boxes.[117] The success of a suggestion box depends on two things. Firstly, it needs to be displayed prominently with enough paper and pens supplied for use. Secondly, the service must look at the suggestions and be willing to address or act on the feedback.

Suggestion boxes have their limitations. Literacy is required and even literate service users may find it difficult to put ideas into words. Suggestion boxes that haven't been acted on by the service become irrelevant. Service users will not continue to make suggestions if they are continually ignored. Or worse, will make 'unhelpful' or abusive suggestions.

If a suggestion box has been sitting in the corner gathering dust, there are some ways to freshen it up.[118]

- Decide on a process for reviewing the suggestions that are made, write this up as organisational procedure and follow it. Include:
  – how the suggestions will be reviewed and by whom (a group of people is best)
  – how regularly they will be reviewed
  – the person/position responsible for ensuring this process occurs
  – how/where will records of this process be kept and how can staff and service users have access to these records
  – how service users will be informed of changes that are made and of changes that will not be made and an explanation of why.
- Make service users aware of the box and the new procedures for reviewing the suggestions and encourage them to use it.
- Consider asking service users at different times to make suggestions about a particular subject or theme.
- Consider having a consumer as part of the group that reviews the suggestions.

Macarthur Drug and Alcohol Service suggestion box[119]

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

A review of foundational practices

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

Moreland Hall's new Client Charter and feedback mechanisms[120]

In 2007 Moreland Hall identified the need to improve its consumer feedback processes.This was a result of a managers' retreat and the involvement of Moreland Hall in the AOD accreditation process. It also was a timely response to the increasing departmental policy requirements that organisations become more client centred. Interested staff were asked to become part of a working group which began by reviewing existing documents relating to consumer participation. These included client's rights and responsibilities information, the complaints process, client satisfaction surveys and client consultation processes such as forums, evaluations and focus groups.

It was decided that Moreland Hall would produce its own Charter of Rights and Responsibilities and would develop feedback mechanisms to measure their performance against the Charter.

The Charter was developed after staff training sessions with the Victorian Commission of Human Rights and Responsibilities and a review of how other sectors handled this issue.

A feedback form was developed with less focus on 'client satisfaction' and more importance placed on clients being able to provide meaningful feedback that could be used to contribute to service review and planning. It was designed to measure service performance against the Charter.

In addition, the complaints process was revamped so that it was easier to understand and use. The same mechanism was implemented for both staff and client complaints with an emphasis on resolving complaints early and in person. A new complaints brochure was developed with a flow chart helping to explain the process.

Input was sought from service users on all three new endeavours. Moreland Hall consulted with existing treatment groups in its service as well as with staff.

The design, language and layout of the Charter, complaints pamphlet and feedback form were changed as a result of this consultation. Moreland Hall also consulted with APSU to ensure nothing important had been overlooked.

The new resources were then trialled for a period of two months. Feedback forms were distributed to most service areas and returned anonymously to the transparent feedback box. It was clear that service users were willing and able to provide significant feedback by using the new form. Minor adjustments were made to further improve the form.
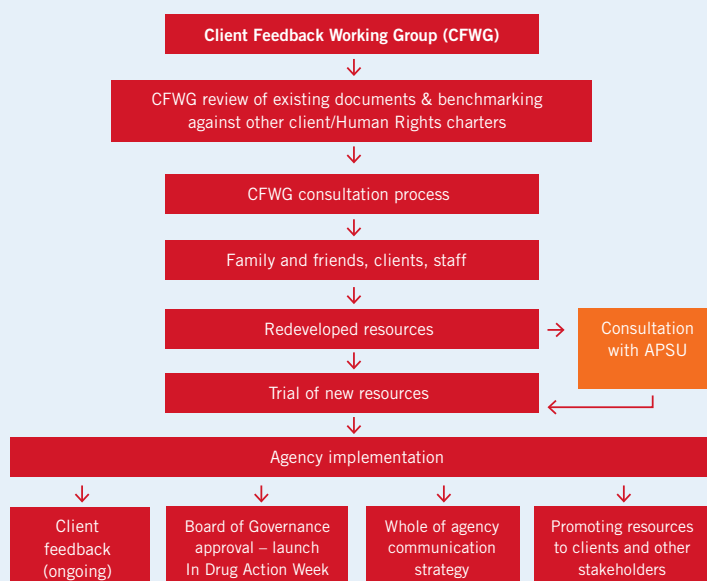

Figure 3: Revising existing practices – Moreland Hall[121]

The Charter is now displayed in waiting areas at all Moreland Hall service sites. An information pack containing the Charter, the complaints process pamphlet and a feedback form is placed in each new client file. This is given to clients by treating staff at an appropriate stage of a client's relationship with Moreland Hall. Feedback forms can be returned anonymously at any time.

Staff have been educated about the redeveloped complaints system and are encouraged to assist in resolving complaints early. Complaints that do make it to a managerial stage are logged and addressed in a similar way to incident reports. A review takes place and common grievances are addressed by appropriate service responses.

Feedback forms are collected every quarter by the working group and a report is written and presented to the senior management team. Some feedback is able to be acted upon quickly, such as providing an explanation about particular procedures, or may inform easily modified aspects of programs. Other feedback may be explored as part of an emerging theme that has implications for other service areas or resource allocation, or be part of other issues that then lead to a focus group or other evaluations.

Clients are kept informed about the content and progress of service user feedback and any changes made are communicated via the Moreland Hall newsletter which is available in the waiting room.

In response to feedback obtained regularly from clients in the adult residential withdrawal unit, Moreland Hall developed its alcohol community rehabilitation program 'Catalyst', a six-week non-residential rehabilitation program for those who have completed residential detoxification.

See the Charter, complaints pamphlet and feedback form in *Appendices 3-5* on pages 111-113

Surveys

Surveys can be used to gauge service user satisfaction, provide information about specific programs or aspects of service provision and also to make suggestions for improving or changing services. Surveys are only considered 'consultation' if some of the information obtained is acted upon and changes are made. Before initiating a survey, services must consider why they want this information and how it will be used. Feedback must be given to clients on how their input has been used.

Surveys are a limited way for consumers to get involved. Surveys gather and communicate certain information and the agenda is almost always set by the service provider, which means consumers have little or no control over the way this information is used.

Some surveys may be done as a matter of course, perhaps as part of an evaluation process for various programs. If the design of the survey is always left up to staff, valuable information may be missed.

When designing a survey for consumers:

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

Turning Point Phase 1 Project – Client satisfaction survey[122]

Turning Point Alcohol and Drug Centre identified a need to increase its service user input and formed a committee of management and staff along with consumer representation from APSU staff. The committee sought to gain feedback about service provision from Turning Point's clients by designing and implementing a client satisfaction survey and holding focus groups (discussed in the example *Turning Point Phase 1 Project - Focus Groups* on page 62).

The survey included a number of self administered demographic, quantitative and qualitative items and was placed in the waiting room with a notice asking clients to complete. 'Front of house' clients using the needle and syringe program (NSP) were also offered the survey by NSP workers. It was decided a timeframe of four weeks for data collection would allow most people using the service a chance to complete the survey. However, after a week, few surveys were completed. Chocolate was then offered as an incentive and the survey notice reworked. This was followed by a dramatic increase in completed surveys with a total of 47 surveys completed over the next few weeks.

The committee analysed both the quantitative and qualitative responses and decided upon changes to service provision. The most significant change to service provision as a result of this project was the introduction of takeaway doses for eligible clients of the pharmacotherapy service.

Clients were informed of the survey results and service changes via a flyer in the same waiting room. There also were reasons given when changes were not made.

Comments

✓ Involved service user representation early in the process.

✓ Involved staff who were enthusiastic about consumer participation and who were willing to implement changes as a result of feedback obtained.

✓ Used more than one method to gain feedback.

✓ Communicated results to clients.

✓ Communicated resultant changes to clients.

> Involved APSU representative to consult on consumer participation strategies. Best practice would be to also include a current Turning Point client on the committee - this is planned for the future.

> Best practice would be to embed a successful survey project into organisational procedures (e.g. include surveys as regular quality assurance tools).

See *Appendix 6* on page 114 for a copy of the survey.

Salvation Army exit surveys – Abbotsford Residential Withdrawal Unit[123]

The Salvation Army Bridge Withdrawal Unit asks all their clients to complete an exit survey upon discharge. Assistance is offered to anyone who expresses difficulty in filling it out. Even people who have an early or unplanned discharge are asked to participate. Around 80% of people admitted to the Abbotsford Residential Withdrawal Unit complete the survey.

A report is written regularly by the manager and is tabled in team meetings. The information obtained is then discussed with the team. Any issues or improvements requiring attention are then addressed with key program staff.

Patient satisfaction in an opioid pharmacotherapy clinic[124]

The Department of Health (NSW) led a project that developed a quality assurance tool for use with opioid dependent people who use government-funded pharmacotherapy services in NSW. The project was carried out at Rankin Court, a clinic at St Vincent's Hospital, Sydney.

The project development and implementation was supported by a reference group which included leading professionals in the AOD sector as well as representatives from the NSW Users and AIDS Association (NUAA).

The project developed an 11 point self administered questionnaire. Service users had an opportunity to contribute to the development of the survey. The survey was then administered over four days by the project officer and a NUAA representative in the waiting room of Rankin Court while service users waited to receive their pharmacotherapy dose. One hundred and seventy five questionnaires were completed. Seven per cent of respondents were assisted by the NUAA representative.

Recommendations from the project to Rankin Court included:

• Services be reviewed in light of survey responses.

• The service review is communicated to service users.

• A satisfaction survey becomes an annual feature of Rankin Court's quality improvement framework.

Recommendations from the project to the NSW Government included:

• The survey tool be used widely in NSW public pharmacotherapy services.

• Other client input tools be developed for other types of drug treatment services in NSW.

Comments

✓ Involved service user representatives early in the development and implementation of the survey.

✓ Used non clinical staff to administer survey ensuring participants were honest and confidentiality retained.

✓ Recognition that the survey was only of use if changes were made to the service as a result.

✓ Good practice to communicate survey results and outcomes to service users.

Interviews

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

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

Interviewer administered survey in a UK pharmacotherapy service[125]

In the UK, a survey was conducted at a National Health Service (NHS) community drug clinic where most of the service users were opiate dependent and receiving pharmacotherapy treatment. Two surveys conducted in 1999 and 2001 used the same questionnaire administered by an interviewer, i.e. an unpaid psychology undergraduate from a local university, who was engaged to increase the authenticity of responses and protect client confidentiality. The survey was designed from a literature review and discussions with staff and clients, and it was piloted and refined before being used.

Service users were recruited from the waiting room of the clinic, informed about the process and asked to sign a consent form. The interviews were paid and took place over a series of afternoons in specific interview rooms. About a third of all clients were interviewed in both years.

Survey results indicated that it was the norm for clients to supplement their pharmacotherapy prescriptions with additional drug use and they were unhappy with dosing frequency but reasonably satisfied with the service overall.

Little change in service provision occurred as a result of the survey. Many of the suggestions for improvement were beyond the control of the clinic, and could only be handled by the pharmacotherapy regulatory body. There was no mention of feedback to clients of the results of the survey or a response from the clinic to the survey results.

Comments

✓ Survey design had service user input.

✓ Impartial interviewers were used to conduct the survey.

✓ Service users remunerated.

> Could be viewed as tokenistic as it was known from the start that most things could not be changed (NB: survey results like this and from other prescribing clinics could be used as feedback to influence decision making on the part of pharmacotherapy regulatory bodies).

> Not good practice to ask service users for their opinion and then not respond to their input. Even a report explaining why changes can't be made is valuable in letting service users know they have been heard and their input is appreciated.

Involving family members in the evaluation of residential rehabilitation services[126]

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

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

• Involving family members in the treatment of problematic substance use is more effective than treatment based solely on the individual.

• Family members have needs that should be considered separately from those of the drug dependent person.

• Despite conflict within families, the dependent person is often still in contact with family members. (It is recognised that families are not always supportive of the client or their treatment.)

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

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

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

Comments

✓ Inclusion of family members as key stakeholders.

✓ Sound recruitment method – Turning Point indicated that the contacts provided were forthcoming because of the trust and rapport built with clients during site visits and focus groups.

✓ The purpose of the research was to provide DHS with a family member perspective, rather than for family members to effect change in the rehabilitation services they were linked to. These aims were made clear to participants.

✓ Family participants able to access final report to DHS.

> Good practice would include DHS notifying family members of intended changes to service provision or policy as a result of this evaluation.

Focus groups

Focus groups can be a great way to ask consumers what they think about a particular issue and, if well managed, can offer a chance for consumers to voice their opinions and be heard. Focus groups are best used to gain detailed qualitative information on a specific issue from a small group of people, although a series of groups will ensure a range of consumers has been consulted.

Focus groups can contain up to 12 people, although typically 8-10 is an ideal number. A series of questions designed to get people thinking is asked before narrowing down to questions focussing on a specific topic. The session is usually recorded (with consent) and notes are taken by a co-facilitator when this is possible. Despite participants being face to face with the facilitator(s), anonymity should be protected as far as is possible. Comments made should not be directly attributable to any individual and recordings should be destroyed or securely stored after transcription has taken place.

A trained facilitator who is not directly associated with the service should run the group. Using an 'outsider' ensures that confidentiality can be maintained, that there is no defensiveness on the part of the service provider, and that focus group participants will feel confident about being honest and forthright in their opinions. Like any consultation activity, focus group participants should receive feedback on how their information was used.

APSU has extensive experience in facilitating service user focus groups.

While focus groups can be rewarding, there are some disadvantages. It can be difficult to organise a time that suits everyone involved, the group itself can be time consuming, especially taking into account the transcription of recordings. Poor attendance can also be an issue. (It was interesting to note that the Service Provider focus group conducted for this handbook was poorly attended compared to the Service User and Family Member focus groups!)

When organising a focus group for consumers:

- Coordinate a time and place that will maximise group attendance.

- Invite more than necessary to allow for poor attendance.

- Provide remuneration or incentives for attendance such as lunch or reimbursement for travel costs.

- Consider how many groups are needed to gain the input required.

- Consider who will be participating in the groups and whether separate groups for service users, family members, females, males, young people, adults are required.

- Develop a list of questions for the facilitator to ask.

- Allow for participants to be late and to take a short break if required.

For more information on how to plan and conduct focus groups go to: http://www.scu.edu.au/schools/gcm/ar/arp/focus.html.

Turning Point Phase 1 Project – Focus groups[127]

Turning Point Alcohol and Drug Centre, desiring to increase its service user input, handpicked a number of staff and clinical managers to form a committee for this purpose. Turning Point then invited service user representation from APSU staff onto the committee. The committee undertook to gain feedback from Turning Point's service users by designing and implementing a satisfaction survey (see example *Turning Point Phase 1 – Client Satisfaction Survey* on page 58) and holding focus groups.

The focus groups were publicised to service users via a flyer in the waiting room which included the payment fee. Service users were asked to give contact details to reception staff if interested in participating. Turning Point clinical staff vetted the list of interested service users to determine appropriate participants. (Some concern was cited for an individual's ability to meaningfully participate in a group or for significant conflict to arise between participants in a group who had existing conflict.) Administration

staff were provided with appropriate information outlining the purpose of the focus group and the processes involved to provide to clients, and then asked to contact the interested service users to arrange two focus groups. Those service users not deemed suitable for a focus group were invited to take part in an individual interview covering the same issues.

It was decided that non-clinical staff should facilitate the focus groups to maximise confidentiality and increase the likelihood of honest feedback. A Turning Point researcher and an APSU staff member were chosen. The two facilitators designed the focus group questions based on what the committee had agreed were areas of interest to Turning Point and its clients based on previous informal feedback from staff and clients.

One focus group was run in the morning, the other in the afternoon and both were conducted on site. Two hours was allocated for each group, which allowed for a late start, an explanation of the process and group agreement, and a break in the middle. Refreshments were provided.

The focus groups were attended by 11 and six people respectively. Notes were taken by one of the facilitators and the sessions were recorded with only the facilitators having access to the recording and participants giving consent. No identifying information for individuals was connected to any comments made.

Participants received $25 cash for their participation from the reception staff immediately after the group. One individual interview was also completed by the APSU representative, the other interested interviewees proving uncontactable.

A report was then written for the committee on the main themes of the focus groups. A further combined report was then prepared using the client satisfaction survey and focus group results. A summary of these results was then developed into a flyer for service users to read, placed in the waiting room and posted to participants. The flyer included a statement of Turning Point's intention to inform clients of any changes made as a result of their feedback.

The committee then analysed responses and decided upon changes to be made to service provision. As previously mentioned, the most significant change to service provision as a result of this project was the introduction of takeaway doses for eligible clients of the pharmacotherapy service. Other changes or reasons for not making changes were communicated to clients.

Comments

✓ Service user representation included early in the process.

✓ Staff who were enthusiastic about consumer participation and who were willing to implement changes as a result of feedback obtained were involved.

✓ More than one method used to gain feedback.

✓ Focus groups facilitated by non-clinical staff and confidentiality maintained.

✓ Participants remunerated and refreshments provided.

✓ Results and changes communicated to clients.

✓ Alternate method of feedback provided for those excluded from groups.

> Decision to exclude some clients from groups may be viewed as problematic.

See *Appendix 7-9* on pages 115-117 for documents relating to these focus groups.

Service user groups

A service user group (SUG) is made up of service users from a particular service who have input into that service. SUGs require planning and resourcing to be effective rather than tokenistic. A SUG may also be referred to as a community advisory group.

A service user group must:

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

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

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

Terms of Reference' is also necessary for a SUG. This can be written by the group in its early stages with staff support. The terms should be agreed upon and approved by the organisation and become part of organisational policy and procedure.

Terms of reference should address the following issues:

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

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

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

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

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

SHARC's Recovery Support Service (RSS) Community Advisory Group[128]

The community advisory group was formed out of the Quality Improvement Community Services Accreditation (QISCA) process where service users were asked to provide input into the standards. This group has since become a formative means of developing and reviewing RSS policy and practices. It is this very consultative process that has built and established not only practices but also leadership amongst the users of this peer based service. The group has been running since late 2006 and replaced the disbanded RSS Steering Committee. Despite running for some time, it is still a work in progress.

The community advisory group is made up of current RSS consumers who meet once a month. At the beginning of each meeting, participants vote on who will chair the meeting and a volunteer is nominated to take minutes. Minutes are then passed on to RSS staff to include in their staff meeting and any outcomes of issues raised are regularly fed back to the group. The group now runs independently when once it was chaired by RSS staff.

Terms of reference are currently being developed for the group. A starting document has been developed and, once completed, the terms will be approved by the board at SHARC. (See *Appendix 10* on page 118 for Terms of Reference.)

Comments

✔ Group runs independently from staff.

✔ Formal process for group feedback to organisation.

> Terms of reference still being developed.

Service user advisory groups

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

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

APSU has a membership of trained service users and can be called upon to assist in providing consumers to form issues based advisory groups.

Eastern Region Alcohol and Drug Strategy Group's Dual Diagnosis Consumer Advisory Council[129]

At the time of writing this handbook, the advisory council is still in the process of establishment. It is included here to highlight the planning and time needed to reach the recruitment stage and the decision making that has been completed so far.

The Eastern Region Alcohol and Drug Strategy Group's Dual Diagnosis Consumer Advisory Council is in part the realisation of the Dual Diagnosis Working Group Action Plan and is based on five service delivery outcomes set out in the Victorian Government's Dual Diagnosis Key Directions and Priorities for Service Development (2007). This Consumer Advisory Council is the realisation of the fifth service treatment objective: 'to strengthen consumer and carer participation and feedback in training, service development and evaluation'.[130]

Working collaboratively with APSU, the Dual Diagnosis Working Group has already:

- Set out the aims of The Consumer Advisory Council including how this committee will link in with the Alcohol and Drug Strategy Dual Diagnosis Group.

- Successfully applied for funding for the financial remuneration (vouchers) of the Consumer Advisory Council members.

- Decided upon training and support of its members.

The Working Group will develop terms of reference that will include protocol for running the group and documenting its activities. Recruitment has been chiefly the work of Knox Community Health and APSU. A flyer was developed with input from the Strategy Group and sent out to the APSU membership base and the Victorian Alcohol and Drug Agency Network. In addition, it was advertised at various services in the eastern region and aims to target people who have used AOD services in this region and have a co-occurring alcohol and other drug and mental health issue.

Once membership has been selected, APSU will deliver training via 'Experts by Experience' workshops. These workshops are designed to train people who want to participate at a governance level.

See *Appendix 12* on page 120 for the terms of reference for the council.

Comments

✓ Collaborative planning for establishment of council.

✓ Development of aims and terms of reference.

✓ Funding obtained for remuneration.

> Use of vouchers for remuneration.

CONSULTATION/PARTNERSHIP LEVEL

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

Peers in service delivery

One of the most common ways for consumers to achieve higher levels of participation in the alcohol and other drug sector is for people with lived experience of alcohol or other drug dependence to be involved in program delivery. Often this occurs in an unknown or accidental fashion, as when ex users are employed, either deliberately or unknown to the employer. However, it is not considered consumer participation unless experiential expertise of a worker is a requirement for the role being filled.

A worker with experiental expertise may not convey the ideas and input attributed to the consumer perspective. There are a number of reasons for this. An ex user who is working in the field may not be called upon to give a user's perspective or may have become so much a part of the professional team that they no longer identify with other drug users. A person 'in recovery' may not have used the service in which they are working and if many years have elapsed since they used drugs. Therefore the pertinent issues of drug and/or service use can be forgotten or seem less important. In addition, people in 'recovery' have often achieved significant goals such as accommodation and employment and it can be difficult for them to truly represent current service users' concerns.

Nevertheless, the deliberate use of peers in program delivery is valuable. This is the case whether the peer is in long term or short term 'recovery', a period of stability or still actively engaged in substance use. Peers are able to create a sense of identification amongst other service users, and may gain trust and credibility with service users more easily than other workers. Peers may have a greater understanding of issues pertaining to drug use and services and often have a wealth of knowledge and skills that can be passed on to other service users.

Sometimes a peer will show bias about a particular issue. They may support a specific treatment method or theory due to their own experiences and this can interfere with their ability to perform peer duties. Education, training and support are essential for peers in service delivery roles.

Education broadens the personal perspective to include other possible experiences and provides an increased awareness and understanding of the service sector. Training teaches peers to be able to appropriately apply their knowledge and skills. Support or 'supervision' is important in any professional role and it is essential in developing the knowledge and capability, i.e. the professional capacity, of a peer worker.

APSU offers education, training and support as part of the FIT Peer Model. A number of training courses have been developed by APSU for people who wish to become involved, not only in peer roles but also in governance. APSU also has extensive experience in supporting and mentoring people engaged in peer work.

Some AOD agencies require an ex drug user who is in abstinence-based recovery to be 'clean' for two years before being employed in any capacity, or to be two years free of having last accessed AOD services. This rule is discriminatory and may contravene equal opportunity legislation.[131] In addition, there appears to be no evidence that people in recovery are 'safe' once they hit the two year mark and 'unsafe' before this time. Certainly it is acknowledged that it takes a period of time to become accustomed to a drug free life and there are many challenges for people in the first and second years of their 'recovery'. However, people in 'recovery' need to make their own decisions about whether they are ready to enter the AOD workforce.

If an agency insists on keeping this 'two year' rule for the purposes of full time employment, there should be leeway for peer based roles. Many peer based roles are voluntary and involve much less responsibility and time than full time employment. Indeed, if a person has been in 'recovery' for two years, they are unlikely to be available for smaller, unpaid roles as they are likely to be engaged in full time study or employment. Lastly, as service users become involved in valued peer roles, as with other consumer participation roles, this can lead to empowerment, an increase in psychological wellbeing and the development of skills and confidence, all of which are conducive to ongoing 'recovery'. (See *Benefits to consumers* section on page 20).

Peer helpers

APSU Peer Helper Training Course[132]

APSU runs a 40 hour training course for people who are in a stable period of 'recovery' and/or have achieved significant treatment goals who wish to help others with their 'recovery'. The training covers topics such as phases of recovery, stages of change, boundaries and ethics, risk assessment, relapse prevention and self care.

After completing the training, peer helpers undertake 12 hours of voluntary peer help in a mainstream AOD service. Many peer helpers then go on to formally study in the AOD area and subsequently gain employment. Others feel confident enough to go on to study in other fields or gain voluntary or paid employment outside of the sector. Some graduates become part of the APSU Speaker's Bureau (see below) or take up other consumer participation activities. Evaluation is obtained regularly from participants.

See *Appendix 13-15* on page 121-123 for the Role and Responsibilities of a Peer Helper, Peer Helper Placement Agreement and the Peer Helper evaluation form.

Peer educators

APSU Speaker's Bureau[133]

APSU has a database of people with personal experience of substance use who are able to speak on various alcohol and other drug related topics to community groups, schools or professionals.

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

An inexperienced speaker is accompanied to the talk by an APSU staff member and debriefed after the session. An unemployed speaker is paid between \$40 – \$80 depending on the amount of time spent and preparation involved.

Comments

✓ The selected peer is suitable for the task and has adequate skills, training and personal resources.

✓ Peer is given adequate support with preparation and attendance and is debriefed after the session.

✓ Peer speaks about general topic rather than personal story.

✓ Peer is remunerated with cash payment.

> Fee does not reflect payment for non-peer presenters.

Harm Reduction Victoria – Peer education[134]

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

When dealing with highly stigmatised behaviours such as illicit drug use and injecting drug use, peer-to-peer information sharing and safe behaviour modelling can have a high degree of credibility and effectiveness in reducing drug related risks. Peers share particular language, cultural rituals, values and beliefs much more closely with each other than with non-peers. Harm Reduction Victoria's peer education model balances the most reliable and appropriate health information from research with an 'insider' understanding of alcohol and other drug use and its related harms.

Adult education provides a useful underpinning for peer education, especially in its more formal aspects, such as workshops and focus groups. Adult education acknowledges the dignity and autonomy of all participants, values their unique skills and experiences and seeks to build upon their expertise through open and honest discussion. It aims for an equality of power between facilitators and participants. In addition, HRVic researches what other educators, scientists and affected people understand about a health issue and uses this as a basis for discussion and 'reality checking' with peer participants involved in workshops and campaigns.

Harm Reduction Victoria recognises that the most effective peer education, in terms of reaching enough people and having a positive impact, is not what happens with a small group of people participating in a workshop. Peer education in its broadest sense is an organic process that occurs spontaneously during interactions between peer group members within their own networks. The kind of formal peer education that happens in workshops etc. is only going to be effective on a wider scale if it taps into or stimulates those organic peer-to-peer processes in the community. The rapid and widespread changes that drug users made to their injecting practices in response to the threat of HIV is an example of how effective peer education and community action can be, even though only a minority of the users involved in those changes would have attended any education or training sessions.

HRVic considers it beneficial for a well-trained and informed peer to facilitate peer education processes. Having the participants recognise the person facilitating or leading the process as a peer is not only likely to be more effective, because of trust and credibility, but can also be empowering. It reinforces the notion of 'doing it for ourselves' and demonstrates that members of marginalised groups have the power within themselves to effect positive change. It is preferable, therefore, to have facilitators of peer education workshops and projects to be as closely peer-related as possible to other workshop participants.

Simply being a peer does not necessarily mean that a person has the skills to do research, facilitate a group or design a health promotion campaign. Campaigns and resources should be peer informed, but developed in partnership with people with appropriate skills. Most importantly, any resource or campaign should be considered a draft until it has been rigorously focus tested for accuracy, relevance, impact and credibility by peers, who should be independent of those who informed the development of the resource. Peers are diverse and any group of people affected by an issue will have sub-groups or 'tribes' with slightly different outlooks, experiences and cultural nuances. An effective resource or campaign will therefore be both peer informed and focus tested by independent peer groups. HRVic suggests that these health promotion principles should apply whether or not the peer groups and context involves alcohol and other drugs.

See example *Harm Reduction Victoria (formerly VIVAIDS)* beginning on page 88 for issues addressed with peer education.

Peer support

Windana peer support groups[135]

Windana Drug and Alcohol Recovery Service operates three peer support groups, one located in St Kilda at the Windana site, one in Dandenong at South Eastern Alcohol and Drug Service (SEADS) Residential Withdrawal Unit and one in Rosebud at Peninsula Drug and Alcohol Program (PenDAP). The groups run for 90 minutes each week and are open to alcohol and drug dependent people who want to get 'clean' and are not intoxicated at the meeting.

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

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

Comments

✓ Clearly defined role.

✓ Transparent selection process.

✓ Well supported by the organisation.

> Requires two year's 'clean time' for the facilitator role.

Peer workers

Peer worker for AIVL's Treatment Service User Project at North Yarra Community Health's Next Door program[136]

As part of the second stage of AIVL's Treatment Service Users Project, Next Door, a service of North Yarra Community Health's (NYCH) Drug Safety Service, was awarded a small amount of funding to undertake a peer worker project.

A peer worker was employed to assist an external project facilitator and key staff from NYCH to identify ways of improving its pharmacotherapy service. The peer selected by management for the role was a regular client of the service and had participated in several consumer participation projects in the past including AIVL peer education workshops and the ANEX conference. The peer worker was paid a sitting fee for each activity and reimbursed for travel costs when required.

In addition to the AVIL training workshops, the peer received training in organisational structure, the AOD sector, meeting processes and advocacy from APSU's 'Experts by Experience' workshops. The peer worker was offered additional support from APSU and the NSP team leader and manager of NYCH Drug Safety Services for the duration of the project. A position description was available to ensure the role and expectations were clear.

The peer worker was involved in fine tuning a survey tool used to elicit feedback from clients about pharmacotherapy services, and then went on to conduct the survey. This person was later involved in training NYCH staff on consumer participation.

Involving a peer worker ensured that survey responses were sincere and the confidentiality of the NYCH clients was maintained. The peer worker had a personal understanding of client concerns, and there was an increased sense of 'ownership' for all service users involved in the process. The peer worker reported an increase in confidence, self esteem and a sense of empowerment as a result of being employed in the role.

There was some dissatisfaction expressed by other service users early on in the project and it was thought that this was due to jealousy about the role and a lack of understanding about the project and its purpose. The peer worker was given extra support and provided with practical strategies on how to handle any conflict, including referring clients to management who could further explain the role and handle complaints. No complaints were formally made by service users. The peer worker also emphasised the potential benefits of having a peer in the role.

Comments

✓ Peer worker effective in soliciting authentic feedback from service users.

✓ Peer worker had appropriate skills, experience and training.

✓ Intensive and accessible support provided by organisation.

✓ Additional support provided by an independent organisation.

✓ Remuneration.

✓ Peer worker treated as an equal by organisation.

> A selection process that was transparent to other service users may have been better as selection by management can be biased. This could have involved advertising the role to other service users and having an interview process based on the selection criteria. This is not always possible with time and resource constraints.

> It is also best if the project has built-in sustainability, especially for the peer worker. It is likely at this particular organisation with its high commitment to consumer participation, that the peer worker will have ongoing opportunities to continue their role in some way.

See position description in *Appendix 16* on page 124.

Peer worker at Ovens and King Community Health Centre's AOD service[137]

Ovens and King Alcohol and Drug Service provides a range of services including withdrawal support, counselling, pharmacotherapy and support groups to people experiencing substance use issues in the Hume region.

In 2006 Ovens and King employed an AOD peer worker for a period of six months. The project was funded by the Commonwealth Department of Health and Ageing. Training for the peer worker covered organisational policies and procedures. Additional support was provided by an AOD counsellor, who 'buddied' with the peer and monthly supervision sessions were also conducted.

The peer worker's role included designing a handbook for service users to assist them in accessing Ovens and King services, designing and implementing a survey which provided feedback on Ovens and King services and determining interest from AOD service users about participating in a service user advisory group

Reports from the project suggested that the peer worker role was very successful. The organisation felt the feedback given by service users enabled them to reflect on their current standards of service provision and the peer worker served as a valuable source of information for clinicians.

The benefits to the peer worker included being employed as part of a team, an increase in confidence to re-enter the workforce and an increase in personal confidence. The peer worker is now studying a Certificate IV in AOD and Mental Health.

In light of the success of the project, Ovens and King has employed another peer worker in an administration role on the 'No Wrong Door' project.

Comments

✓ Clear role and position description documented for the peer worker.

✓ Appropriate remuneration.

✓ Training and support provided by organisation.

✓ Despite the project not being sustainable, the organisation has continued to explore ways of using service users to increase consumer participation.

> It is ideal if some additional support can be offered from an independent organisation, especially a consumer organisation.

See *Appendix 17* on page 125 for position description.

Peer worker in the Healthy Liver Clinic, Turning Point Alcohol and Drug Centre [138]

A pilot project, The Healthy Liver Clinic, was set up by Turning Point Alcohol and Drug Centre in 2006. The clinic involved a multidisciplinary team which included a peer worker from Harm Reduction Victoria (formerly VIVAIDS). The clinic ran for over 12 months in 2006-2008 and ceased due to a lack of funding. During its operation, 167 service users accessed hepatitis C education, screening and assessment. Thirty-three service users initiated treatment with 22 completing the six or 12 month course.

Harm Reduction Victoria was involved in the design of the clinic and supported the peer worker throughout. The role of the peer worker was to provide broad based education, advocacy and service user support. Because of the presence of the peer worker, the clinic had a strong emphasis on service user perspectives. This had a positive effect on service user engagement and retention, and on treatment uptake and outcome. Service users said they felt more confident to initiate treatment due to the peer support available, and that this support helped them stay on this difficult treatment. Peer involvement also led to empowerment amongst service users; those who didn't wish to embark on treatment had advocacy support from the peer worker to have their wishes respected by the treatment focused clinicians, while those who did begin treatment were more likely to be active in their own treatment.

The Healthy Liver Clinic was enormously successful in its operation and a great many service users were disappointed with its early closure.

Peer volunteers at SHARC's Family Drug Help [139]

Family Drug Help (FDH) is a peer based service of the Self Help Addiction Resource Centre (SHARC) that provides support to families of people who experience problematic substance use. One of the main services is a telephone helpline, staffed by people who are family members of substance users. The helpline coordinator advertises through Volunteers Victoria and their own service users for interested people to undergo training to become FDH volunteers. FDH uses a peer based model, and applicants are required to have the experience of alcohol and other drug use in the family, allowing them to have a greater understanding of caller issues.

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

The volunteers have a lot of passion and enthusiasm as they like the idea of being able to support callers and 'make a difference' to other families.

Experiential workers

Many alcohol and other drug agencies employ workers who have personally experienced substance dependence. Some agencies prefer to employ experientialists and have 'personal experience' as a key selection criterion. Other agencies have formal or informal practices of welcoming experientialists amongst their staff or keeping a balance between experientialist and non-experientialist workers. Some agencies, however, discourage the practice and candidates for employment are best advised to keep their experience to themselves.

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

Consumer consultants

Consumer consultants are the mainstay of consumer participation in the mental health sector and have been working across the 22 area mental health services in Victoria for over 10 years. Although their role is sometimes unclear, consultants act as a liaison between patients and clinical staff. Their role may involve helping patients with complaints, explaining the treatment process, or assisting clinical staff in providing the best possible care for patients. Consumer consultants can sometimes walk a fine line between the patients whose interests they are there to represent and the service that employs them.

While possessing many similar qualities, mental health and AOD services are very different. One of the main differences is that AOD treatment service users are almost always voluntary recipients of treatment, and this is often not the case for mental health service users. For this reason, it is essential that mental health consumers have easy access to consumer consultants or advocates and have immediate assistance with understanding their own treatment and care in order to increase the possibility of having a voice.

It is not envisaged by APSU at this stage of consumer participation in the AOD sector to encourage the use of agency based consumer consultant roles of the type that exist in the mental health sector. Although Client Liaison Officers have been employed with some success at some AOD agencies, the role can be ill defined and leave the peer worker isolated from other staff, unsupported in a difficult role or 'caught between' the clients they serve and the agency that employs them.

For the role of agency based consumer consultants or consumer advocates to be developed within the AOD sector there would need to be:

- Sufficient funding to pay workers (this role should be in addition to clinical staff, not instead of).

- Payment received from an independent or consumer body rather than the agency.

- Clear roles and responsibilities for the consultant.

- Sufficient education, training and professional support, also adequately funded.

Staff selection

In the AIVL survey on consumer participation activities, it was found that only 11 per cent of AOD services interviewed had service users involved in the recruitment of staff.[140] Service users have valuable input to offer in relation to the recruitment of staff and have successfully been incorporated at times into the staff recruitment process in mental health services.[141] Benefits include improving relationships between services and service users as well as having a greater level of support for consumer participation.[142]

Unfortunately, consumer participation at this level occurs very infrequently, with only 20 per cent of AOD service providers saying they would be willing to include service users in staff selection processes. This differs considerably from the opinions of service users, with over 50% saying they would be willing to participate in this type of activity.[143] Service providers gave the following reasons for their lack of participation: they were 'concerned about the practicalities', 'felt that consumers were inadequately skilled' or 'were unsure of the appropriateness or value of having service users involved'.[144]

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

SHARC service users in staff selection[145]

Chief executive officer – 2006
During a combined managers meeting at SHARC, it was advocated that a current service user representative be on the panel for the selection of the chief executive officer at SHARC. Each of the managers nominated a service user. The process decided that a service user from each of the three service areas meet and decide amongst themselves who would be the best to represent this group. The selected consumer was briefed by the chair of the SHARC board and then participated in short-listing applicants and was a member of the three-member selection panel. The service user was also briefed and debriefed by the APSU manager.

Peer Helper campaign coordinator (APSU) – 2008
The service user representative for this panel was a person who had completed the peer helper training and was selected from several other peer helper graduates as the peer advocate for this campaign. Although the representative was briefed on the staff selection process, after participating in the selection panel, the person stated they did not realise they had helped appoint a coordinator who would directly supervise them.

Chief executive officer – 2008
After the success of the August 2006 position the process became part of SHARC recruitment policy. The same process was applied to the selection of the service user for the August 2008 recruitment, that is, each service area nominated services users who then decided amongst themselves who would fill the role. The service user was briefed by the chair of the SHARC board, and briefing and debriefing processes to ensure the wellbeing of the service user representative were performed by APSU. The service user participated in the short listing process and in the three member selection panel.

Recovery Support Service manager – 2008
In this case, the service user representative was selected by the acting manager of RSS. The person was briefed by APSU ensuring they had the necessary information to fully participate in the decision making process. The representative was also debriefed when the successful applicant was announced.

After the success of the aforementioned selection processes, SHARC has now included service user involvement in staff recruitment procedure. It is a requirement that each selection panel for any staff position include a current service user.

Comments
✓ Service user representative chosen from amongst several candidates and supported by a (small) group of service users.

✓ Service user given some training by chair of board.

✓ Service user briefed and debriefed by those aware of consumer participation concerns.

✓ Consumers on recruitment panel now organisational policy.

✓ Remuneration was via training and experience provided rather than cash.

> Nomination process by management has potential to be biased and doesn't allow for autonomous decision making on part of consumers.

> Open selection of a representative by the group could be done by secret ballot.

> Extra training may be required to decrease possibility of misunderstandings and to enhance the utility of this role.

> Selection criteria could be developed for this role.

Next Door service user involvement in staff selection [146]

Several service users have been involved in staff selection panels at the North Yarra Community Health Drug Safety Service 'Next Door'. Staff are asked to nominate a suitable client to fill the recruitment panel position and the selected person then receives training from the manager in the process of recruitment and the expectations of the role. It is explained that the service user will sit in on interviews and be required to ask some questions of the applicant. They will then give their feedback about an applicant to the other panel members who will decide on the successful applicant.

Comments

✓ The use of service users in interview panels communicates to prospective staff the commitment the organisation has to its service users.

✓ Service user has appropriate level of responsibility and receives training.

> Nomination of service users by staff has the potential to be biased.

Odyssey House staff selection [147]

Odyssey House Victoria operates a therapeutic community for people recovering from alcohol and other drug misuse. Rehabilitation residents can be involved in staff selection in a number of different ways. Residents interact with prospective staff by taking them on a tour of the service. Residents feed back to staff selectors about potential new employees. Residents may participate in group interviews or staff selection panels and are nominated for these tasks by clinical staff.

Comments

✓ A range of methods are used depending on the availability of suitable service users, time and staff resources.

Service users in staff selection at two UK drug services[148]

Health Options Team (HOT)

This East London service provides harm reduction services including a needle exchange program and employs about 12 staff. Service user involvement occurs within a culture of existing consumer participation. Involvement in staff selection was originally sporadic as appropriate service users were not always available and staff were often needed to fill roles quickly. A process was developed where service users who could devote a half day to training were included.

Training covered:

- Confidentiality and equal opportunity.

- Understanding the job description and role specification.

- Introductions and the role of the service user in the interview process.

- Interview questions and probing for information.

- The use of internal scoring forms for rating applicants.

Over a four year period, 11 new staff were recruited at HOT and service users were involved in the interview panel four times. Some applicants were asked to spend time in a 'drop in' setting with service users who gave structured feedback to the interview panel on the applicant's communication skills.

KCA

KCA is a south London and Kent service providing a range of programs to drug users including needle exchange, counselling, pharmacotherapies and day programs, employing about 200 staff in various locations.

Using protocols developed by HOT, KCA recruited service users to become involved in staff selection. Five service users were trained in the recruitment of 12 out of 50 staff over a six month period. Service users were involved in short listing candidates, interviewing applicants, role plays and the decision making process. Service users were paid and given travel expenses for each recruitment episode.

KCA has now set a target of involving service users in 50 per cent of all staff appointments.

Comments

✓ Some service users nervous about their role, this decreased as experience was gained.

✓ Service users, even those not directly involved, experienced greater 'ownership' of service.

✓ New staff experienced first hand demonstration of commitment to 'client centred' service.

✓ Quality of staff recruited improved, especially in the area of service user engagement.

✓ Good practice to provide training to service users for this high level participation role.

✓ Persistence over a long period of time for both services.

✓ Remuneration.

✓ Procedure written into policy and targets developed.

Quality assurance

Quality assurance is a process that most AOD services must undergo in order to remain accountable. It is an opportunity for service providers to directly involve service users in the evaluation of the effectiveness of their programs.

SHARC service users in the QICSA process[149]

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

The benefit of including service users in the process conveyed an important message that service user input was valued. The young people at RSS felt personally valued and their views were considered relevant and worthwhile. The organisation had the benefit of gaining another, 'outside' perspective on their processes, and the inclusion of service users in such a formal process over a long period of time led to greater consumer participation within the organisation overall. The inclusion of service users on staff recruitment panels (see example *SHARC service users in staff selection* on page 75) and the formation of a service user group (see example *SHARC's Recovery Support Service (RSS) Community Advisory Group* on page 65) were a direct result of this process.

Comments

✓ Service users included were given sufficient training and support to provide meaningful feedback.

> Ideally an independent person would assist service users to give feedback so that feedback wasn't influenced by staff.

Odyssey House service users in quality assurance[150]

Odyssey House Victoria operates a therapeutic community (TC) for people recovering from substance misuse and takes part in an annual quality assurance process with the 'Communities of Communities'. Standards for Addiction Therapeutic Communities have been developed and a community is encouraged to have all its members contribute to the self review including current and ex service users. Odyssey House TC discusses the standards with residents and ex residents, staff and management. A combined and agreed upon report is then sent to Communities of Communities in the UK. The report is also used at Odyssey House to inform change.

Strategic planning

Consumers can be involved in strategic planning for an organisation or program area. It is essential that service users receive some preparation before attending a planning day or that the day is designed with service users in mind.

SHARC consumers in strategic planning[151]

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

Although the best method for service users to contribute to strategic planning is to attend personally, if an organisation does not feel confident to involve service users or there is resistance then other methods can be used. Surveys, focus groups and other feedback conducted prior to planning can form the means by which service users views are included in strategic planning.

Salvation Army – focus group for strategic planning[152]

A focus group was held to provide clients and ex clients of Salvation Army AOD services with the opportunity to contribute to strategic planning in 2008. APSU sent invitations to anyone on their database who had used Salvation Army AOD services and offered a $40 remuneration fee. The focus group was held at Turning Point during the day.

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

PARTNERSHIP LEVEL

In a partnership there is a move towards joint decision making. Consumers and services jointly own the process and outcomes of a project. Although using peers in service delivery can be considered a partnership activity, peers often do not have equal say in service delivery and so this has been discussed in the *Consultation/ partnership* section on page 67. This section will focus on consumer involvement in committees.

Consumers on committees

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

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

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

Consumer representatives

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

In practice, given the lack of formalised groups of service users and consumer participation in general in the AOD sector, it is difficult for consumer representatives to truly represent a group of consumers. However, many, consumers, having had training or contact with other consumers over the years, are able to incorporate others 'stories' into their views and think in broad terms about alcohol and other drug issues and service delivery. It is for this reason that these consumers are able to fulfil the consumer representative role despite having no formal ties with large groups of consumers.

Consumers on organisational committees

MonashLink Improved Services Initiative – Project steering committee[153]

MonashLink is a community health service that includes AOD counselling. The Improved Services Initiatives project officer was responsible for recruiting a service user representative (with experience in both alcohol and other drug and mental health issues) to the project steering committee.

Although a service users' group had been discussed at MonashLink, it was currently not up and running. As such a service user representative could not be recruited from an established group. It was felt that this representative role was time sensitive and should be filled as soon as possible. The project officer researched existing peer support groups in AOD agencies and in mental health but was unable to find any information to help with the recruitment process. The project officer also approached counselling staff at MonashLink who were unable to help due to concerns about using client contact information for non therapeutic matters.

Harm Reduction Victoria (formerly VIVAIDS) and APSU were approached and both groups sent out an advertisement to their databases. In total six service users responded. APSU agreed to assist with the selection process.

APSU and MonashLink discussed and developed the following selection process:

- All respondents received a letter or phone call from APSU informing them of the selection criteria and an appointment for an informal interview.

- APSU and MonashLink's project officer jointly interviewed the respondents and of the six, three people were able to attend the interview.

- A service user representative for the project steering committee was chosen from the three applicants. The two unsuccessful applicants were asked if they were interested in being part of a service users group and their contact details were retained.

MonashLink conducted an orientation to the project for the representative. APSU provided an abbreviated one-to-one training session on consumer participation, meeting processes and self care for the representative. The APSU project worker attended the first two steering committee meetings to provide support and debriefed the representative after the meetings. Ongoing support is available to the representative.

As stated previously, counsellors at MonashLink felt it would be a breach of confidentiality to pass on client contact details to the project officer, so it was difficult to recruit from MonashLink's own client base. A problem such as this can be overcome by using a consumer participation consent form for all clients (see *Recruit service users* section on page 48). A flyer in the waiting room was the only other way of contacting clients and was seen as too impersonal to be successful.

When recruiting for dual diagnosis purposes it does not really matter if a service obtains a representative from the AOD sector or the mental health sector, however, it is probably more practical to source a representative from within an organisation's own sector.

Comments

✓ Several methods were attempted in recruiting the consumer representative.

✓ Remuneration provided.

✓ Training and support offered.

✓ Clear and transparent method of selection.

✓ Successful applicant had direct experience of the service.

> Unfortunately the service user representative was not selected until the steering committee had already met several times. This makes it harder to participate in the meeting process and to understand what is going on. The representative may also have missed out on setting terms of reference or priorities for the organisation.

> A service user representative should be in contact with a group of service users that they represent. This was not achievable in this situation.

See *Appendix 18-20* on pages 126-128 for more information.

SHARC Improved Services Initiative – Project steering committee[154]

It was decided that two service areas of SHARC, APSU and the Recovery Support Service (RSS) would be suitable for recruiting a service user representative for the project steering committee. Two APSU members were nominated by APSU's manager. The RSS community group of residents met and selected three potential representatives themselves. (Family Drug Help (FDH), a third service area, had already provided a family member representative for the committee.)

The successful representative was to be remunerated $40 per committee meeting with the money being provided by Improved Services Initiative funds.

A meeting was set up for the five candidates who were asked to prepare a short presentation about their suitability for the position and their evidence of fitting the selection criteria. After this, a secret ballot was conducted and a suitable representative was chosen.

The selected representative already had experience in meeting processes and so was not given any training from APSU. The representative was briefed on the project and currently receives ongoing support/ supervision from APSU.

Comments

✓ Transparent selection process.

✓ Adequate support.

✓ This representative has formal contact with a group of services users on an ongoing basis.

> Selection process could be seen as biased as APSU manager selected APSU representatives.

Steering committee for APSU

The purpose of the APSU steering committee is to represent and advocate for the interests of people in Victoria who use alcohol and other drug services, personally or by family association and/or friendship. This is achieved via the provision of advice, guidance and knowledge to the service manager, participating in APSU activities as required, assisting the manager to evaluate the effectiveness of the services, and providing input to strategic planning.

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

The committee meets once every two months and an agenda and manager's report is mailed out a week prior to the meeting. Committee participants are encouraged to contribute to the agenda. A meeting is only held when there is a quorum of two service users and one provider. Each participant is expected to attend at least three meetings a year, to provide conceptual input and leadership. SHARC's CEO attends twice a year and is responsible for the ongoing resourcing of the steering committee.

The process of recruiting service users developed over a number of recruitments and was adjusted, following evaluation. For the past two recruitments this process has been followed:

- A letter is sent out to APSU members who have completed APSU training requesting those who are interested in applying to contact the APSU manager.

- The APSU manager compiles a list of interested people and arranges an interview time with one of the APSU steering committee members. A letter is sent to the applicants that includes selection criteria. Applicants are instructed to prepare a response to each of the criteria.

- Questions are developed and agreed upon.

- Interviews are conducted and led by the APSU steering committee member. The APSU manager provides administrative support.

- Applicants are selected based on how they respond to the criteria.

- Successful and unsuccessful applicants are informed accordingly. Feedback is provided to the unsuccessful applicants and they are invited to apply again in the future.

- A kit is provided to the successful applicant that includes the terms of reference, APSU's mission, meeting dates and times, and information about SHARC.

Members are not renumerated financially for their time. However, the participation in the APSU steering committee is considered an opportunity from which further opportunities arise. Additionally this pivotal role is one that impacts substantially on the development of APSU and is greatly desired. This is evidenced by the significant numbers that respond when these positions are advertised.

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

Comments

✓ Terms of reference developed.

✓ Committee is part of SHARC governance.

✓ A fair recruitment process.

✓ Members are trained and supported.

✓ Part of organisational governance.

✓ Remuneration via non cash methods.

> Turnover of members.

> Different perspectives are not always represented.

> Availability of members for strategic planning days can be problematic.

See *Appendix 21* on page 129 for the Terms of Reference

Consumers on other committees

Family Drug Support representation on committees[155]

"Family Drug Support was formed after its founder Tony Trimingham lost his son to a heroin overdose. Bereft, Tony felt frustrated by the general apathy and ignorance of his own experience and discovered his was the plight of many other families. Realising this was but the tip of the iceberg, a public meeting was called where hundreds of people attended. Family Drug Support (FDS) was formed as a result."[156]

FDS' mission is to assist families throughout Australia to deal with drug issues in a way that strengthens relationships and achieves positive outcomes.[157] Along with his role as Chief Executive Officer, Tony Trimingham acts as a family advocate and representative on numerous committees and boards including:

- Board of The Alcohol and other Drugs Council of Australia (ADCA) which is the peak, national, non-government organisation representing the interests of the Australian alcohol and other drugs sector, providing a national voice for people working to reduce the harm caused by alcohol and other drugs.[158]

- Delegate to the 2009 Drugs Policy Modelling Program Roundtable on illicit drug policy in Australia. The Roundtable was an effort to address the need for new and forward-looking collective thinking about illicit drug policy. Twenty-seven leaders and experts in drug policy from around Australia met in Canberra to discuss priority issues for illicit drug policy.[159]

- Executive of the Family Alcohol and Drug Network (FADNET) which is a network of professionals with an interest in family based solutions to alcohol and other drug problems. FADNET aims to increase awareness, share practice wisdom, and promote research on family inclusive policy and practice within the AOD and related sectors. FADNET also aims to influence awareness of the impact that alcohol or drug misuse can have on family members and to increase support of their needs.[160]

Comments

✓ Family representation on numerous committees.

✓ Representative in contact with large number of family members and can realistically represent this group of consumers.

> As the representative is a paid worker there is potential for bias (see *Bias of paid consumer representatives* on page 29).

APSU representation on committees and reference groups

Part of the role of APSU is to provide consumer representation and advocacy on reference groups and advisory committees and this has been achieved via a range of projects such as the AOD Withdrawal Practice Guidelines, the review of the Safe Drug Using series at ANEX (Association for Prevention and Harm Reduction Programs) and Moreland Hall's Catalyst Program, a non-residential rehabilitation program for alcohol misuse.

There are times when it is appropriate to have an APSU representative or a representative from Harm Reduction Victoria on a committee or reference group. This may be particularly the case when the project is short term or when there is not enough time to recruit an appropriate consumer. Clearly an individual employed in an AOD advocacy role with a contact base or membership is more likely to be representative

than a consumer who has no contact with other consumers. For example, APSU consults with its membership when working on particular systemic issues, whilst delivering training or contributing to policy. When combined with an insider's knowledge of the service system an AOD advocate's participation in committees or reference groups can be meaningful.

However, there are disadvantages with engaging a worker employed as an advocate or representative. Firstly, a worker is more likely to have distance from the use of AOD services. Secondly, representation of AOD consumers may be contingent on the contact with a particular membership group that may not include particular groups. For example, APSU's contact with rural consumers is not as extensive as metropolitan and regional Victoria. Therefore the potential to represent these views meaningfully is limited. The same can be said for people from other diverse backgrounds. Lastly, advocacy services mostly are funded by government and consequently cannot truly be independent.

Overall, a consumer is preferable as a consumer representative when the project is long term, there is clarity regarding the role, they are the best representative for the community that is directly impacted by the service or policy, and they have the necessary knowledge, skills, training and resources.

Perhaps there is already current consumer input from a focus group or committee. A representative could be nominated from this group. This is best considered during the setup of the reference group.

Comments

✓ APSU is in formal contact with a large number of consumers.

> Regional and CALD views are under represented.

> As the representative is a paid worker there is potential for bias (see *Bias of paid consumer representatives* on page 29).

Consumers on boards of management

Odyssey House Victoria board of management[161]

Odyssey House regularly has an ex resident on its board of management.

SHARC board of governance[162]

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

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

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

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

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

SHARC is in the privileged position of being an organisation that was created by consumers and is staffed mainly by consumers or 'experts by experience'. This means it is possible for the organisation to have numerous contacts within the 'recovery' community and with people who have direct experience of alcohol and other drug issues. In addition, there is a ready source of members with sufficient knowledge and skill to participate as board members.

Comments

✓ A majority of board members are 'experts by experience' and therefore have significant power in decision making.

✓ Consumer participation in organisation's constitution.

✓ 'Experts by experience' already have skills and expertise required for board membership, therefore training is not required.

✓ Board membership is complemented by non 'experts by experience' with specific skills or knowledge.

> The consumers on the board are (usually) ex service users (of any service) and are thus removed from the concerns of current service users of SHARC. There still needs to be significant consumer participation from current service users.

CONTROL LEVEL

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

Narcotics Anonymous

"Narcotics Anonymous is a non profit fellowship or society of men and women for whom drugs have become a major problem. We are recovering addicts who meet regularly to help each other stay clean. This is a program of complete abstinence from all drugs. There is only one requirement for membership, the desire to stop using. Our program is a set of principles written so simply that we can follow them in our daily lives. The most important thing about them is that they work."[163]

Narcotics Anonymous (NA) is an international, community-based association of recovering drug users with more than 43,900 weekly meetings in over 127 countries worldwide.[164]

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

Narcotics Anonymous strives to be entirely self-supporting through member contributions and does not accept financial contributions from non-members. Based on the same principle, groups and service committees are administered by NA members, for members.[165]

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

In a country where Narcotics Anonymous is a relatively new and emerging fellowship, the group meeting is the only level of organisation. In places where a number of Narcotics Anonymous groups have had the chance to develop and stabilise, groups elect representatives to form a local service committee and these committees offer a number of services, including:

- Distribution of NA literature.

- Helpline information services.

- Presentations to treatment and healthcare staff, civic organisations, government agencies and schools.

- Presentations to acquaint treatment or correctional facility clients with the NA program. Maintenance of NA meeting directories for NA members and for other interested people.

In some countries, especially those where Narcotics Anonymous is well established, a number of local/area committees come together to create regional committees. These regional committees handle services within their larger geographical boundaries while the local/area committees operate local services.

An international delegate assembly known as the World Service Conference provides guidance on issues affecting the entire organisation. Primary among the priorities of NA World Services are activities that support emerging and developing NA communities and the translation of Narcotics Anonymous literature.[166]

Comments

✓ Narcotics Anonymous is an effective grass roots association that continues to run itself despite the relapsing and remitting nature of addiction.

✓ All positions of leadership and responsibility are filled with its own members although occasionally non members may be employed for specific tasks.

✓ NA has been present in Victoria for over three decades and there is at least one lunchtime and one evening group every day of the year in Melbourne. It costs nothing to attend.

✓ Narcotics Anonymous is in control of its own resources.

Self Help Addiction Resource Centre (SHARC)[167]

SHARC is a peer based non-government organisation whose mission is: "To provide opportunities for individuals, families and communities affected by addiction and related problems to recover and achieve meaningful, satisfying and contributing lives".

SHARC has three program areas:

- Recovery Support Services (RSS) – a residential program for young people
- Family Drug Help (FDH) for families affected by a loved one's problematic substance use
- Association of Participating Service Users (APSU)

SHARC is funded by the Victorian Department of Health as well as other government departments and philanthropic trusts

As a peer based organisation, SHARC places importance on lived experience of addiction and its effects. This is reflected in SHARCs governance and staff selection.

The SHARC constitution requires that two thirds of the board members are people who have personally experienced addiction or have personal experience of a family member's addiction. This is referred to in the constitution as being an 'expert by experience'. The steering committees that guide FDH and APSU also have this requirement.

Staff recruitment policy states that the value of lived experience is considered in all recruitment to SHARC programs. The majority of position descriptions include 'personal experience' or 'direct experience' as one of the key or desirable selection criteria. The other selection criteria for positions relate to the relevant skills, qualifications and experience for the position.

Comments

✓ Consumers engaged in all aspects of governance and have control of resources.

✓ Consumers involved in program delivery.

> A peer based service must still have mechanisms for current service user participation.

Harm Reduction Victoria (formerly VIVAIDS)[168]

Harm Reduction Victoria Inc, (HRVic) is a statewide membership based organisation, managed and staffed by peers, which promotes the health and rights of drug users. Membership is made up of current users, ex users and people whose aim is to increase information and education about illicit drug use so that people who use drugs experience minimum harm to themselves. HRVic also represents the issues, experiences and aspirations of people who use illicit drugs to service providers, policy makers and the wider public.

HRVic receives government funding to increase the knowledge and understanding amongst drug users about blood borne viruses, overdose and other issues of concern about illicit drug use.

HRVic's role currently includes:

- Education and, in particular, peer education to reduce drug related harms
- Health promotion
- Research collaboration
- Advocacy, policy advice and community awareness
- Support, advocacy and referral for people in opioid replacement pharmacotherapy

HRVic's statement of mission and objectives is:

1.1   As the state-wide user organisation, Harm Reduction Victoria's mission is to be a drug user-based and user-governed organisation. We promote a harm reduction approach to drug use, with a philosophy of self-determination and empowerment. Harm Reduction Victoria aims to provide a voice for people who inject and other users of illicit drugs, and to address the health and social justice issues experienced by people who inject and other users of illicit drugs.

1.2   Harm Reduction Victoria objectives:

(a) To be a drug user-based, user driven and user governed organisation for people who inject and other users of illicit drugs.

(b) To address the issues of blood borne virus transmission and infection amongst people who inject drugs, through peer education, peer support and advocacy.

(c) To promote the reduction of drug related harm.

(d) To provide non-judgemental advocacy, support and referral to people who inject and other users of illicit drugs.

(e) To initiate and participate in ongoing community debate and discussion of issues affecting people who inject and other users of illicit drugs.

(f) To represent the views of Harm Reduction Victoria, and its constituents, to government and non-government bodies.

(g) To challenge social and legal barriers to the health and well being of people who inject and other users of illicit drugs in Victoria.

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

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

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

Some of the projects HRVic runs are:

• Pharmacotherapy Advocacy, Mediation and Support (PAMS)

• Peer education: prevention, management of overdose and drug-related adverse drug effects (DOPE)

• Peer education, prevention and management of drug-related harms in the dance-party scene (DanceWize)

• Peer-based treatment, support and education around Hepatitis C (Hep C)

• Peer education, prevention and management of harms for young injecting drug users (YDUP)

HRVic also produces the user magazine WHACK, which contains contributions from its membership as well as health promotion material written from a peer perspective and presented in such a way as to be widely understood and have lasting impact.

CONSUMER INVOLVEMENT IN EDUCATION AND TRAINING

It is interesting to note that in the four 'manuals'[169] on consumer participation that were used in the development of this handbook, none referred significantly to the role of consumers in the education of professionals working in the areas of health, mental health, housing or alcohol and other drug treatment. As the research conducted by AIVL demonstrates, service providers are most reluctant to include consumers in activities directly relating to staff, including education and training.[170]

There are two aspects of educating workers:

Consumer participation

The first aspect of educating workers is to train professionals in consumer participation. The task of developing and promoting this training has largely been undertaken by the Consumer Focus Collaboration[171] and is supported by the work of the Health Issues Centre. The mental health and AOD sectors have produced various documents,[172] seminars and training workshops in order to promote and train professionals in the benefits and strategies of consumer participation. Unfortunately it appears that many of these valuable documents have remained unread by those working directly in service provision, education, research and policy. This is understandable given the high demands on workers and the almost negligible time and resources allocated to the development of these skills in the workforce.

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

APSU recommends that a competency based unit on consumer participation is developed, in conjunction with consumers, for the Certificate IV in AOD.

This would ensure that new entrants to the AOD workforce understand the value of consumer participation and how to go about developing and maintaining practices in their workplace. Other professional educational bodies would also do well to incorporate consumer participation as part of core material in training courses.

The consumer perspective

The second aspect of educating professionals is that of providing the 'consumer perspective' to the formal training arena. This means that instead of considering every aspect of learning from the point of view of the expert, the student/trainee has input from service users who are able to provide insight and learning on 'how it is for consumers'. This rarely involves the use of detailed personal stories but rather the use of brief anecdotal experiences of many consumers in presenting a key message. Although few and far between, several examples have shown that using consumers in key educational roles has benefits that include enhanced/less stigmatised attitudes towards consumers, a greater willingness to include consumers in participatory roles[173] and encouraging practitioners to think of the consumer before acting in certain, potentially harmful ways.

Currently, the role of consumers in providing a consumer perspective to professionals in mental health is largely limited to 'one off' sessions or guest lecturing.[174] In APSU's experience this is also the case for the AOD sector. While absolutely necessary, unfortunately this activity is at the lower level of participation, perhaps that of 'consultation'. A true partnership of consumers in the education and training of staff would entail consumer involvement in the development and delivery of course material.

Consumers training professionals in consumer participation[175]

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

Family providing the consumer perspective in a 'guest lecturer' capacity[176]

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

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

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

If the person selected is not a staff member, FDH provides training and support to this person by allowing them to observe someone else's presentation beforehand and by attending their presentation. Debriefing is provided afterward.

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

Comments

✓ Family member presents a perspective rather than 'telling their own story'.

✓ Family member receives appropriate training and support and debriefing.

✓ Family member is remunerated with a gift or gift voucher.

> Staff performing this role, due to their employment, have an increased level of power and often some distance from the individual who is currently impacted by a significant others' addiction.

> Non cash remuneration.

Involvement of service users in medical students' education[177]

In 2001, Wentworth Area Health Service (WAHS) Centre for Drug and Alcohol Medicine was approached to provide education to first year medical students from the Western Clinical School in NSW.

Consumers involved were required to be stable and have a variety of treatment experiences and social circumstances. Western Clinical School provided subsidised transport costs and a gift voucher of $20 reimbursement. WAHS provided support for the service users and a brief overview of AOD issues to the medical students. Service users told their 'stories' to the medical students in a supported environment.

The clinical school found that the provision of quality education to medical students was meaningful to their future practice and that the WAHS AOD service was promoted to medical students as a legitimate, quality service.

Clients were provided with the opportunity to participate equally in the promotion of alcohol and other drug interventions. They were also able to express themselves within the context of health in a respectful environment. This provided them with an opportunity to view themselves and their personal experiences as valuable.

Comments

✓ Respectful use of service users in medical students' education.

✓ Remuneration provided although cash is preferred.

✓ Although the use of individual personal stories is not generally recommended, this is an instance where those receiving the education would have had little previous exposure to personal stories and benefited from hearing these detailed accounts.

✓ Support given to clients from staff.

> It is essential that clients are properly briefed and debriefed, especially when sharing personal stories. Often a person can feel exposed and vulnerable after having 'shared too much'.

Involvement of service users in dual diagnosis training[178]

The Victorian Dual Diagnosis Education and Training Unit (ETU) involves service users and family in the delivery of its online training. This is in line with Service Development 5 of the Dual Diagnosis Key Directions and Priorities for Service Development: 'consumers and carers are involved in the planning and evaluation of service responses'.[179] Working with APSU and the Victorian Mental Illness Awareness Council (VMIAC), the ETU set up sessional positions for dual diagnosis experiential educators.

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

Recruitment occurred via APSU and VMIAC.

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

• Experience of co-occurring alcohol and other drug and mental health issues.

• Current capacity to carry out all required functions of the role.

• Commitment to completion of training units and delivery of at least three rounds of training.

• Demonstrated ability to complete the online facilitation course.

• Demonstrated ability to communicate knowledge to a group.

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

These experiential educators are remunerated at $50 an hour as per sessional training payment. Support and mentoring is a collaborative effort of APSU, VMIAC and the ETU and will be provided while the educators complete online training and delivery of online sessions.

Comments

✓ Clear aims developed.

✓ Timeline developed.

✓ Recruitment process fair and transparent.

✓ Financial remuneration and training opportunities provided.

See *Appendix 22* on page 130 for Job Description

TaskForce and Lantern consumer led training[180]

TaskForce, an alcohol and other drug service and registered training centre desiring to increase its consumer participation, joined with Lantern (formerly Reachout) mental health service to produce a consumer led dual diagnosis training course for TaskForce staff. A group consisting of three staff and one mental health consumer consultant was formed to drive the project. This group ran a series of fortnightly meetings over several months with a core working group of about 10 TaskForce service users to develop content for the training course. These ideas were then taken by a staff member in the group who had expertise in education and training and developed into a six module competency based dual diagnosis training course. The working group was consulted regularly as the modules were developed.

The working group chose several of its members to deliver the training while others assisted in a technical capacity. The chosen consumer trainers underwent TAA (Training and Assessment) training. The consumer consultant acted in a support and mentor role to the consumer trainers.

The six module course was delivered by the consumer trainers over six sessions in 2009 and included a consumer perspective on treatment services and how well various practices worked for consumers. The training was well received by TaskForce staff who evaluated the course very positively.

Consumers involved in the project were not remunerated with cash but were provided with refreshments at meetings, given vouchers and received training.

Comments

✓ Staff training designed and led by consumers

✓ Consumers adequately trained for the role of trainer

✓ Consumers adequately supported

> Consumers adequately remunerated although vouchers used

CONSUMER INVOLVEMENT IN POLICY DEVELOPMENT

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

The principles required for meaningful policy participation are the same as for those in the organisational domain (see *Principles and practices* on page 30 and also *Organisational committees* on page 84).

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

CONSULTATION LEVEL

Victorian Drug Treatment Services Satisfaction Survey[181]

As a way of consulting consumers about the services they received, The Department of Human Services in Victoria (now Department of Health) conducted a survey in 1999 of clients and family members. Information was sought on how people felt about the services they received, which treatment strategies were most suitable and the barriers to treatment.

Telephone interviews were conducted with 619 service users through agency consented contact details. A very high level of satisfaction amongst AOD service users was reported, with 83% of clients rating the overall quality of service they received as 'excellent' or 'very good'. Agency staff received the highest performance rating, with 84% of clients rating agency staff in general as 'excellent' or 'very good'.

Four key factors were identified as being important to consumers when seeking treatment at an AOD service and these were:

- staff
- initial contact and how it was handled
- the range of services, and
- the ability to input into one's own treatment and service.

The priorities identified for improving overall quality of service were:

- range of services provided
- service user input into services
- the initial contact experience, and
- the agency rules and procedures being clear and making sense to service users.

Also identified as needing improvement were the physical conditions of the services and the quality of information provided to clients.

Comments

✔ Survey included clients and family.

> Telephone interviews may not have been the best way to elicit feedback as many service users have irregular telephone access.

> Feedback may not be completely authentic in an interview with a non-peer.

> Ideally service provision would change as a result of this feedback.

> Ideally service users would be informed of the results of this survey and any changes made to services as a consequence.

Focus groups for A New Blueprint for AOD Treatment Services 2009–2013[182]

Focus groups were run as part of the development of the Victorian Government's initial Blueprint Discussion Paper from January 2007 to May 2007. Four focus groups in all were attended by an average of 15 people per group. Two groups were run in Bendigo at the Bendigo Community Health Service and two were run in Melbourne at Turning Point Alcohol and Drug Centre.

The first two focus groups (one in Bendigo and one in Melbourne) aimed to elicit the opinions and ideas of consumers (family and service users) regarding the Victorian AOD service system. Questions were asked in relation to the following themes:

• How did people first get involved in the drug treatment sector?

• How did they find out about a needle exchange program?

• Did people find it simple or easy?

• What sort of things would have helped?

• What is good about treatment?

• Pharmacotherapy issues

• Counselling

• Recovery

• Accommodation

APSU used its membership database to recruit the Turning Point focus group participants. People were paid $30 to participate and catering was provided. For Bendigo, a flyer advertised the focus group. However, most people attending were members of a service user group that already met regularly. Generally the same participants that attended the first focus group in each location attended the second.

The second focus groups were used to inform the participants of the information included in the initial discussion paper and to obtain any additional comments from participants.

Both of the focus groups were facilitated by Department of Human Services (DHS, now Department of Health), Drugs Policy Branch. Notes were taken by the manager of APSU and DHS staff. DHS did not record the interviews as it was felt that this may impede participant feedback.

Consumer feedback informed the contents of the initial discussion paper and was used in the Blueprint including information regarding service provision, better collaboration with other service systems, review of the pharmacotherapy model, better counselling practices and improved worker skills.[183] However the themes around childcare whilst undertaking alcohol and other drug withdrawal or rehabilitaion were altered to emphasise the care of the child.[184]

Comments

✓ Service users and family were informed of the outcome of their feedback.

✓ Consumer views included in the writing of the discussion paper.

✓ Views from both regional and metropolitan Victoria obtained.

✓ Service users and family came to understand aspects of the policy making process.

> Participation was contingent on APSU membership and Bendigo Community Health Services usage.

> Attendance was mostly service users. Consequently the family perspective was not well represented.

See *Appendix 23* on page 131 for flyer sent to APSU membership

PARTNERSHIP LEVEL

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

Development of the Victorian AOD Charter[185]

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

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

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

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

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

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

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

Victorian Charter of Rights and Responsibilities (2006)

The International Covenant on Civil Political Rights (1966)

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

Recruitment was achieved via APSU membership and contacts from the agency where the group was being conducted. Participants were paid $30 to attend and lunch was provided.

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

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

A draft was sent to all participants and to services identified as part of the brief for comment. The charter was submitted to DHS for input and a final copy was agreed upon in November 2007.

Comments

✓ Representation from different groups.

✓ Consultative process where people had opportunity to provide input.

> Rural voice under-represented.

> Charter yet to be published.

> Only two family representatives participated.

See example *Victorian AOD Charter (draft)* on page 53 for the draft charter.

CONSUMER INVOLVEMENT IN RESEARCH

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

The most thorough approach to involving consumers in research is termed community based participatory research (or participatory research or participatory action research) and has long been recognised as a way of developing more relevant responses to health care issues than traditional research is capable of providing.[186] It involves consumers being equal partners in deciding priorities for research, the methods used and the analysis and dissemination of the results. In this way research is able to be more relevant to the people who are being researched or studied.

Community based participatory research is said to have the following benefits:[187]

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

While participatory research (see *Control level* on page 101) is at the highest level of consumer involvement, consumers may also contribute to research by defining outcome measures, commenting on methods and by assisting with data collection.

CONSULTATION LEVEL

Drug users consulted on quality of life indicators[188]

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

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

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

Comments

✓ A shift in deciding what is important in treatment outcomes.

✓ Focus groups a good method for eliciting qualitative information.

✓ Large number of focus groups allowed several subgroups' views to be explored.

> Remuneration provided but vouchers used.

CONSULTATION/PARTNERSHIP LEVEL

Peer researchers used to interview parents who use drugs[189]

In the UK, a multi-agency Drug Action Team (DAT) was interested in finding out the needs of parents who use drugs. DAT was keen for researchers to talk to parents in treatment as well as those not using services. Due to the extremely sensitive nature of parents using drugs, it was felt that peer researchers would present the best pathway for interviewing treatment users and also access to non service users.

Two peer researchers were obtained from one of the agencies that had already been engaging peers in survey interviews and other consumer participation roles. These interviewers were recruited to work in relevant geographical areas. Another two were required for a second area. Recruitment proved more difficult as there was little existing consumer participation activity. Nevertheless, agency staff selected two people with the necessary skills and level of stability for the role.

All four peer interviewers received appropriate training according to their previous level of skill and experience. Professional support and supervision was given throughout the lengthy period of interviews.

Support for the peer interviewers was required as it was felt that exposing the peer interviewers to people who were perhaps using drugs in a chaotic way might put them at risk. Supervision was largely provided by co-workers. In hindsight, the peer interviewers said that it would have been preferable to have peer support sessions, especially with more experienced interviewers acting as mentors.

Fifty two interviews were carried out with parents who were using DAT services mainly interviewed by experienced researchers. All of the non service using parents were interviewed by the peer researchers.

Peer interviewers were reimbursed for each interview and the hours spent in training. However, they spent many unpaid hours in discussion, undergoing supervision or more generally in relation to the research project.

Researchers felt distanced from the raw data (few of the interviews were able to be recorded due to interviewee refusal). In allowing others to conduct interviews, the researchers 'were forced to relinquish a degree of control over an area of expertise we felt we owned'. Nevertheless, the peer interviewers obtained useful information that would otherwise not have been gained.

Comments

✓ Peer interviewers used to access hard to reach groups and obtain sensitive information.

✓ Good use of networks in recruiting the peer interviewers.

✓ Adequate training provided.

✓ Appropriate remuneration.

✓ Ongoing support and supervision provided.

✓ Peer interviewers given some input into interview design and the overall project.

> Although there appears to have been great respect for the peer interviewers, it seems it was difficult for the researchers to share their power with non professionals.

> Unpaid supervision and discussion time.

Peer researchers at Burnet Institute[190]

The Burnet Institute is one of the leading medical research and public health institutes in Australia. About 300 scientists and public health professionals are based at its laboratory facilities and main office in Melbourne. Amongst numerous other public health concerns, the Burnett Institute conducts research into alcohol and other drug use from a public health perspective.

An example of recent research is the Melbourne Injecting Drug User Cohort Study (MIX), which seeks to provide a longitudinal picture of injecting behaviour both of heroin users and the increasing number of injecting amphetamine users. It is hoped that the results of this extensive project will assist in forming appropriate policy responses to this major health issue.

The MIX project involves the recruitment and follow-up of around 1,000 young injecting drug users. Data for the MIX study is collected by the AOD fieldwork team, a mixed peer/non-peer team of about 10 staff. The team conducts outreach-based fieldwork with the support of a mobile van and collects information from people who use drugs across a number of Melbourne suburbs. The data collection (interviewing and some blood testing for HIV, hepatitis B and C) is the core task of the fieldwork team but they also provide sterile injecting equipment, health education and referrals.

The peer researchers are recruited in several ways, including through networks developed during previous AOD research and through recommendations from other community workers or NSP workers.

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

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

The Burnet Institute provides on the job training in relation to conducting interviews and workplace safety and peer researchers are provided with specific training in pre and post test counselling for HIV and hepatitis C. Field workers are also trained in how to take blood from potential research participants if that is required for the study they are working on.

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

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

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

The peers working on the MIX project have limited involvement in the study design, though many of the current studies build on the learning achieved from peers involved in previous research projects. Peers are equally involved in the recruitment and the interviewing of participants. There are a range of ways in which fieldworkers are expected to participate in the research - the identification and recruitment of potential participants and weekly participation in team meetings. There are also other ways in which people doing the fieldwork can contribute to new research questions which come up as a result of their fieldwork and from talking with research participants about issues that arise in their day to day lives.

Although usually the domain of more senior research staff, the peer researcher may have an opportunity to assist in the write up of the research data, depending on the individuals' level of interest and skill.

It is essential to make sure that peer researchers are ready for this kind of job - it can be very confronting working all day with people who are still actively using drugs and if the peer worker's own drug use is not in perspective, there may be a greater chance of relapse. Also, boundaries between workers and participants can be very blurred and need to be addressed.

Comments

✓ Peer interviewers used to access hard to reach groups and obtain sensitive information.

✓ Good use of networks in recruiting the peer researchers.

✓ Adequate training provided.

✓ Appropriate remuneration.

✓ Ongoing support and supervision provided.

✓ Peer interviewers given some input into interview design and the overall project.

✓ Appropriate professional respect for the peer researchers maintained.

> Peer researcher may benefit from organised peer support.

CONTROL LEVEL

Consumer led research – Impact of pharmacotherapy costs[191,192]

This research project came about following a conversation between James Rowe (a consumer who also works as a researcher at RMIT) and the Manager of the St Kilda Crisis Centre. The discussion involved the difficulty consumers had in paying for their pharmacotherapy as indicated by the anecdotal evidence of consumers asking the crisis centre to provide financial assistance for their doses. A local doctor was also aware of the problem and had submitted a petition to the Department of Human Services to assist consumers with their pharmacotherapy costs. Unfortunately, the Department declined to move on this issue stating there was a lack of evidence that dispensing fees caused harm to consumers. This response provided an impetus for the research.

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

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

"Consumers are the true experts on the effects of dispensing fees and the way in which it affects them – without their input there is no way such a report could be done".[193]

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

The results demonstrated that the impact of dispensing fees on people who were receiving pharmacotherapy treatment in Melbourne was detrimental to consumers and their ability to enter the program and remain in treatment. A number of recommendations have since been made to the Victorian Department of Human Services as a result of this research; however none of these have as yet been taken up.

Comments

✓ This project was effectively controlled by a consumer although the researcher is not employed as a consumer researcher.

✓ Enabled consumer input into policy process.

> Researcher is not employed as a consumer researcher.

A prison based participatory action research project[194]

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

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

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

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

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

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

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

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

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

Comments

✓ Professional researcher gave full control to consumers and acted as consultant.

> Consumers' power limited by environment and by the negative perceptions of some staff.

AIVL – Treatment Service Users Project[195]

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

In 2005, AIVL conducted a consumer driven research project aimed at exploring the current practice of consumer participation in Australian AOD treatment services.[196] In collaboration with the National Centre in HIV Social Research (NCHSR), AIVL conducted surveys and focus groups of service providers, service users and other relevant stakeholders to determine the levels of consumer participation in the AOD sector and the opinions of providers and service users about consumer participation.

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

The results of this project[197] have created a knowledge base about consumer participation in the AOD sector and have been used to inform the writing of this handbook.

Comments

✓ Consumer led research on a topic of interest to consumers.

✓ Consumers partnered with professional to create robust research results.

RESOURCES

CONSUMER PARTICIPATION

Publications

1. Consumer Focus Collaboration, 2000, *Improving Health Services through Consumer Participation: A Resource Guide for Organisations,* Department of Public Health, Flinders University, and the South Australian Community Health Research Unit, Commonwealth of Australia

   A comprehensive and practical manual on consumer participation in general health services.

2. HomeGround Services and Rural Housing Network Ltd, 2008, *Consumer Participation Resource Kit,* Council to Homeless Persons

   An easy to read manual on consumer participation in the Housing and Homelessness Assistance sector. Covers many issues relevant to the AOD sector.

3. NSW Health, (2005), *A Guide to Consumer Participation in NSW Drug and Alcohol Services*, NSW Department of Health, Sydney

   A NSW based guide to consumer participation in the NSW AOD sector. Some good Australian examples given.

4. Standing Conference on Drug Abuse, 1997, *Getting drug users involved*, SCODA, London, UK

   A UK guide to participation in the AOD sector. Some interesting and innovative examples given.

5. Payne C, 2009, *'Hume Region Alcohol, Tobacco & Other Drugs Consumer & Carer participation Project',* Goulburn Valley Health Service, Shepparton

   An in depth look at AOD consumer participation in Australia and Hume Region ATOD consumer participation activities and strategic plan included.

6. Hinton T, 2010, *Voices on Choices: working towards consumer-led alcohol and other drug treatment,* Social Action and Research Centre, Anglicare, Tasmania

   An in depth look at consumer participation in the UK and its lessons for Australia with recommendations for a consumer participation framework in Tasmania and Australia.

Organisations

Association of Participating Service Users (APSU)

140 Grange Road, Carnegie, Vic 3163
Phone: (03) 9573 1778 Fax: (03) 9572 3498
Email: apsu@sharc.org.au
Web: www.apsuonline.org.au

Harm Reduction Victoria (formerly VIVAIDS)

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

Health Issues Centre

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

Victorian Mental Illness Awareness Council (VMIAC)

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

INDIGENOUS

Organisation

Ngwala Willumbong Cooperative Ltd

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

CULTURALLY AND LINGUISTICALLY DIVERSE

Publications

1. Department of Human Services, 2006, *Cultural Diversity Guide: Planning and delivering culturally appropriate human services,* Department of Human Services, Melbourne

2. Romios P, McBride T, Mansourian J, 2007, *Consumer Participation and Culturally and Linguistically Diverse Communities: A Discussion Paper,* Health Issues Centre Inc, La Trobe University, Melbourne

Organisations and resources

Drug Info Multicultural Website

– Victorian multicultural AOD services directory

– Cultural competency training for organisations

– Research on CALD drug use and treatment

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

Drug and Alcohol Multicultural Education Centre

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

Centre for Culture, Ethnicity and Health

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

GAY, LESBIAN, BISEXUAL, TRANSGENDER AND INTERSEX

Organisations

Gay and Lesbian Health Victoria	www.glhv.org.au
People Living with HIV/AIDs Victoria	www.plwhavictoria.org.au
Rainbow Network	www.rainbownetwork.net.au
TransGender Victoria	www.transgendervictoria.com
The ALSO Foundation	www.also.org.au
Victorian Aids Council and Gay Men's Health Centre	www.vicaids.asn.au
Way Out	www.wayout.org.au

DISABILITY

Publications

How to advise staff on disability awareness. Job Access, Australian Government website, http://jobaccess.gov.au/ Employers/Supporting_and_retaining_staff/Disability_awareness/Pages/How_to_advise_staff.aspx

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

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

APPENDICES

Appendix 1: SHARC consumer participation policy draft

SHARC POLICY AND PROCEDURES

sharc

OP 007 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 practice that is utilised by all services under the SHARC umbrella.

PURPOSE

The purpose of SHARC Consumer Participation Policy is:

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

RESPONSIBILITY

Chief Executive Officer   SHARC Staff
SHARC Management   SHARC Consumers

DEFINITIONS

Consumer Participation

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

Consumer

A consumer is a community member who has been impacted by alcohol and other drug use. 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 power as knowledge and skill increase
10. Acknowledged in written or verbal form for their contribution, skills and participation to pass on to prospective employers, or to support further education opportunities.

Improvement

1. Consumer participation activities at SHARC are audited every two years by the Management team at SHARC.
2. This Audit is to include a list of activities, the outcomes of these activities, and aims for future improvement.
3. Audit of activities and outcomes to be included in CEO Report to the SHARC Board of Governance.
4. Consumers contribute to audit of consumer participation activities

Page 1 of 2

SHARC POLICY AND PROCEDURES

sharc

Evaluation

Various evaluation practices can be used for each project or committees. These can include focus groups, surveys or presentations. Evaluation outcomes are to be documented as part of the improvement system. If projects cannot be evaluated then this is to be communicated to SHARC management for discussion at Combined Managers Meeting

Terms of Reference

These are developed in conjunction with the committee or advisory group and passed on to the Executive Officer for approval by the SHARC Board of Governance.

Reporting of Steering Committee and Community Advisory Group Activity

This to be included in reporting to the SHARC Board.

Staff Training and Orientation

1. Simple assessment of staff skills and knowledge of consumer participation is to be conducted yearly by service manager with the assistance of APSU. Four hour training workshop on consumer participation is to be delivered if the need is identified.
2. Staff orientation is to include access to Consumer Participation Policy and a quick assessment of knowledge and experience in consumer participation.

Practices at SHARC

Consumers participate in the following at SHARC:

Strategic planning	Evaluation
Planning days	Facilitation of groups
Delivery of professional training	Consumer driven projects
Recruitment	Network activities or partnership presentations as requested
Quality Accreditation	Complaints process
Audits	
Advisory groups	
Steering Committees	

SUPPORTING DOCUMENTATION

HRE 001 Staff Recruitment and Retention
HRE 005 Staff Orientation
HRE 006 Code of Ethics
HRE 008 Staff training, Development and Supervision

Authorised by: Heather Pickard	Position: CEO
Date of Issue: July 2010	Last Reviewed: August 2010
Review Date Due: August 2012	Status: Current

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Appendix 2: Monash Link and APSU's combined consumer participation consent form

MonashLink's drug and alcohol counselling team is called EDAS, which stands for Eastern Drug and Alcohol Service. EDAS is constantly improving its programs and services. If you have used our services or are currently using our services, we would like to hear about your experience.

If you are interested in contributing your ideas on how we can improve what we do, please fill in the from below so that we can contact you as opportunities to participate arise.

Name_____

Address_____

Phone_____

Mobile_____

Email_____ Services Used: Counselling

Other   (Please circle)

Signature_____ Date_____

MonashLink works with the Association of Participating Service Users (APSU) to ensure that the input we get from our service users is the best that it can be. APSU is the state-wide service that helps people who use Alcohol and Other Drug services to have their say in how these services could be improved. MonashLink –EDAS encourages you to also fill in the APSU membership form below.

APSU Membership Application (Free)

I wish to become a member of APSU. I would like to:

☐ Receive the quarterly APSU 'FLIPSIDE' magazine

☐ Be sent information on how to become involved   (Please tick)

I am a: ☐ service user   ☐ service provider

☐ family member   ☐ other   (Please tick)

Name_____

Address_____

Phone_____

Mobile_____

Email_____

Please detach and send to APSU 140 Grange Road, Carnegie, Vic, 3163

Appendix 3: Moreland Hall Client Charter

UnitingCare
Moreland Hall

CLIENT CHARTER

You are entitled to expect and receive high quality services at Uniting Care Moreland Hall (Moreland Hall).

The Purpose of the Charter

This charter describes your rights and responsibilities when you participate in our services.
It is a partnership to help you achieve the best possible outcomes.

Rights

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

Responsibilities

As a client of Moreland Hall I am expected to:
* contribute to an environment that is safe and supportive for everyone
* treat all people and their property with respect and dignity
* provide accurate information on issues that affect my treatment
* respect the privacy of others

Providing feedback

Feedback is important whether it is a compliment about treatment or an expression of dissatisfaction or concern. Feedback assists Moreland Hall improve its services. Any feedback that I give will not prejudice my treatment at Moreland Hall.
I can expect to:
* be given opportunities to provide feedback based on my experiences of treatment through Moreland Hall
* be listened to whether I have a compliment, a complaint or a concern
* be able to raise my concerns directly with the person involved
* raise a concern or make a formal complaint using the Moreland Hall complaint's procedure
* be able to bring a support person with me while I provide feedback
* receive feedback about ways I might be able to improve the outcomes of my treatment

Privacy

Moreland Hall abides by the appropriate privacy and health records' legislation. I may request the Privacy Statement at any time.

Other relevant services and resources:

Information Privacy Act 2000 and Victorian Health Records Act 2001
Office of the Health Services Commissioner: Ph (03) 8601 5200 or Toll free: 1800 136 066
The Uniting Care Moreland Hall information is all available: Ph (03) 9386 2876 or www.morelandhall.org
Uniting Care Moreland Hall Privacy Statement
Uniting Care Moreland Hall Release of Information statement
Uniting Care Moreland Hall "Complaints Process" brochure

The Client Charter is consistent with the Department of Human Services AOD Client Charter
and the Victorian Charter of Human Rights and Responsibilities

Appendix 4: Moreland Hall complaints process pamphlet

Still not satisfied?

If, after following the complaints process described in this brochure, you are still not satisfied that your complaint has been handled in a fair and reasonable manner you can refer it to the State Health Services Commissioner.

Contact details

Office of the Health Services Commissioner
Complaints and Information
Phone: (03) 8601 5222
Toll Free: 1800 136 006

Or write to

Office of the Health Services Commissioner
30th Floor, 570 Bourke Street,
Melbourne 3000

UnitingCare Moreland Hall

Has been providing alcohol and other drug services since 1969

Our main centre is located at
26 Jessie Street
Moreland 3058

Telephone:
(03) 9386 2876
Fax:
(03) 9383 6705
Email: queries@morelandhall.org
www.morelandhall.org

UnitingCare
Moreland Hall

(V2.1 Feb 2008)

UnitingCare

Complaints process

Information about what to expect and who can help you

UnitingCare Moreland Hall is an Alcohol and Other Drugs Treatment and Education Service of UnitingCare Victoria and Tasmania

Making Complaints

UnitingCare Moreland Hall (Moreland Hall) welcomes you to provide feedback about the services you receive.

Moreland Hall welcomes you to provide this directly to the person or service concerned.

If you are dissatisfied with the outcome you may wish to make a complaint.

You may want to have a support person with you at any time through this process. The support person may be a friend, relative, outside professional, or Moreland Hall's Chaplain. The Chaplain may be contacted on 9386 2876.

How to make a complaint

1. Talk with the staff member concerned
2. If that person is unavailable, speak with his/her supervisor.
3. If you are still dissatisfied you may make a complaint in person, in writing or over the phone to the Manager of the relevant service.
4. The Manager may need to talk to you to get more details and to discuss your complaint.
5. We will write and let you know what is happening, and when you can expect a full response.

Complaints Process Flow Chart

You have an issue

Discuss with person → Problem Addressed

Still dissatisfied

His/her supervisor → Problem Addressed

Still dissatisfied

Service Manager → Problem Addressed

Still dissatisfied

CEO → Problem Addressed

Still dissatisfied

At any time you may contact
Office of the Health Services Commissioner
(see back cover for contact information)

Anonymous complaints

It is often difficult for Moreland Hall to respond to an anonymous complaint.

Your anonymity will limit the action Moreland Hall can take to resolve the complaint.

Resolving a complaint

If service standards, procedures or policies have not been followed you will receive a written and/or verbal explanation.

The outcomes may also include:

• an apology
• services provided by a different counsellor
• changes in the way services are provided in the future
• assistance to access other suitable services
• changes in Moreland Hall's Policy and/or Procedures
• disciplinary action against staff concerned

The final outcome of your complaint will be discussed with you and you will receive a summary of the outcome in writing.

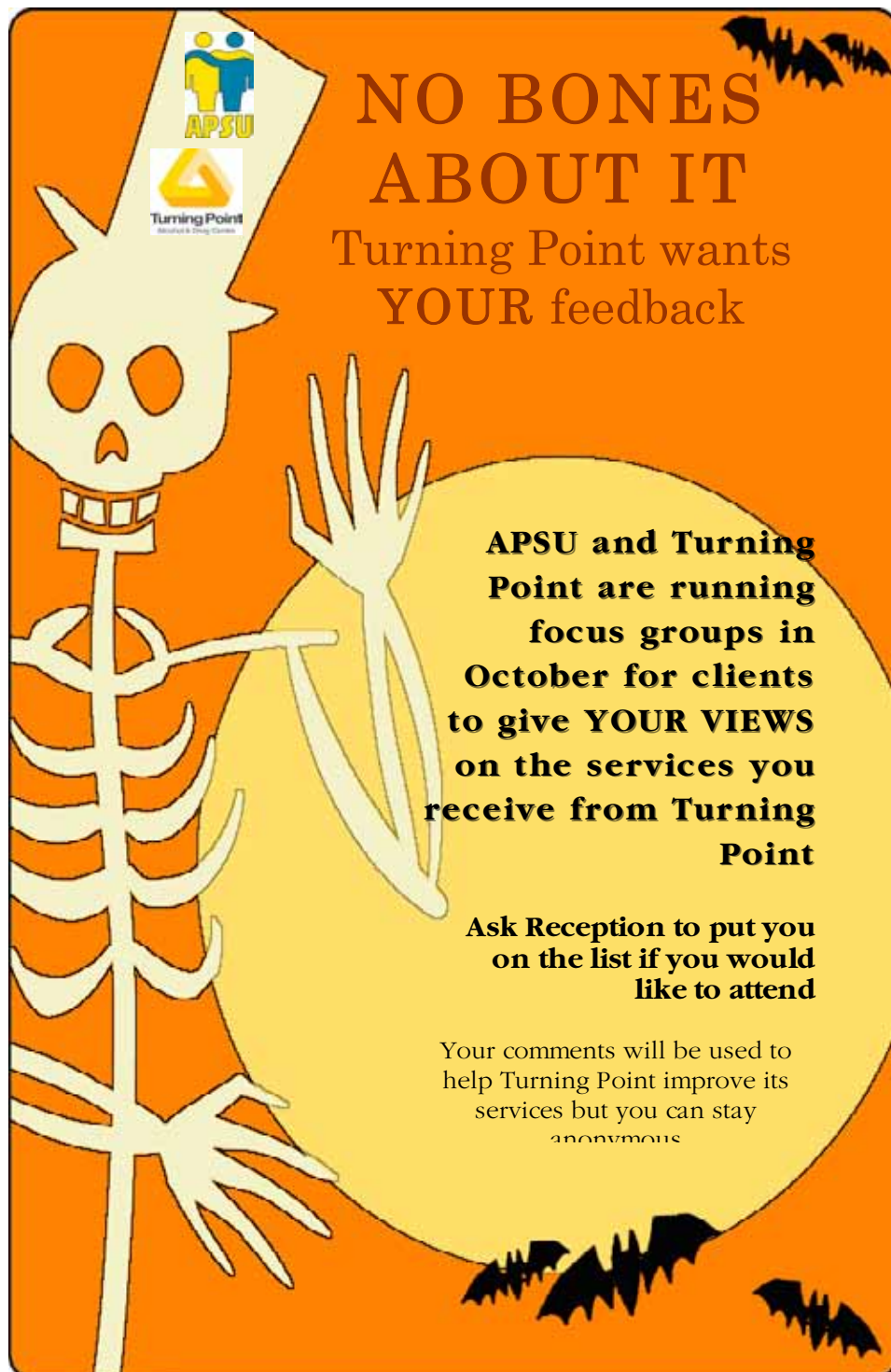## Appendix 5: Moreland Hall client feedback form

Appendix 6: Turning Point Phase 1 client survey

Turning Point Client Survey – Improving Turning Point's Services

Turning Point is working with APSU to improve our services. We want to hear about your treatment experience. This brief survey is anonymous and will not impact your treatment at Turning Point.

Gender   Male   Female   Age _____

1. **I have been with Turning Point for:**

   c Less than 1 month   c 1 month – 1 year   c Over 1 year

2. **I am satisfied with my overall treatment at Turning Point:**

   c Yes   c No   c Don't know

3. **My Turning Point experience has changed for the better:**

   c Yes   c No   c Don't know

4. **I receive:**

   c Counselling   c Pharmacy   c NSP   c Medical   c Nursing   c Access Point

5. **Which services, if any, are you satisfied with?**

   c Counselling   c Pharmacy   c NSP   c Medical   c Nursing   c Access Point

6. **Which services, if any, are you not satisfied with?**

   c Counselling   c Pharmacy   c NSP   c Medical   c Nursing   c Access Point

7. **My treatment goal was to :**

   c Use less alcohol
   c Stop using alcohol
   c Use less other drugs
   c Stop using the following drugs
   : _____
   c Have less problems related to my drinking
   c Have less problems related to my other drug use
   Other goals _____

8. **My treatment at TURNING POINT helped me achieve:**

   c Some goals   c All goals   c No goals   c Don't know

9. **Do you have mental health needs:**

   c Yes   c No   c Don't know

   a. **If so are these needs being addressed:**

      c Yes   c No   c Don't know

   If interested please complete the additional questions over page

---

What has worked well with your treatment?

What has not worked well in your treatment?

How has the quality of your treatment changed since you've come here?

What would you like to see changed at Turning Point?

How welcoming is the waiting room?

What would you change about the waiting room?

What do you think attracts people to Turning Point?

What do you see as the good things about Turning Point?

What do you think stops people coming to Turning Point?

What do you see as the bad things about Turning Point?

Other comments

**Turning Point is running focus groups to gain feedback from our clients.
If you would like to participate please contact staff in the CLINIC/RECEPTION to be involved.**

Appendix 7: Turning Point Phase 1 focus group flyer

Appendix 8: Turning Point Phase 1 focus group participant letter

Participant Name
Participant Address

Date

Dear

Thank you for agreeing to be part of our series of client focus groups.

As you may be aware, the focus group you attend will consist of 8-12 Turning Point clients who will give their opinions about the treatment services they are receiving. Turning Point is interested in hearing your views so that we can use this information to make our services the best they can be.

Miriam Clarke from APSU (an independent organisation that helps clients have their say) and Bridget Roberts from our research team will be running the group so that you can be honest in your feedback without worrying about it affecting your treatment. Your views will be passed on to Turning Point so that services can be improved but your name will not be used.

The group will go for about an hour and a half, we will serve a light snack and you will be paid $25 for your attendance.

Your focus group is:

<div align="center">

Day 00th Month
Turning Point
54 – 62 Gertrude St
Fitzroy Vic 3065
10.00 am – 00.00pm

</div>

Please see reception in person or call on 0000 0000 to confirm that you still intend to come. If you can't make it please let us know and we may be able to swap you into another group.

On the day, please report to the front reception and you will be shown into the right room. We look forward to seeing you then.

Regards,

Clinic Practice Manager   Project Worker
Turning Point   APSU

Appendix 9: Turning Point Phase 1 client focus groups running sheet and questions

Turning Point Client Focus Groups – Running Sheet

Preamble

- Welcome
- Introductions and explanation purpose of focus group
- Going to be asking a series of questions
- Real names will not be used when the info is passed on
- Info will be recorded for note taking purposes but will then be destroyed
- TP will receive the info/answers to questions and a committee will change the things that can be changed easily, harder things will be referred to the executive committee or the board. Some things will take time to change and some things may not be able to change at all.
- You will be given a report on what has happened to your ideas (next year)
- Mobile phones off

The Questions

- We're going to ask several questions and you will all have a chance to answer, there are no wrong answers; we are after your opinions
- We are not trying to all agree on the one answer but want to hear many different viewpoints
- If you disagree with someone else, that's ok, you do not need to convince anyone else to think the same thing as you do
- Only one person should speak at one time

Focus Group Questions

Warm Up
1. **What is your name and your favourite meal?**
Background
2. **What alcohol and other drug treatment services have you used?**
3. **What TP services do you use?**
General Comments
4. **What do you like about TP services?**
5. **What don't you like about TP or the services you use here?**
Key Questions
6. **What would you like to see changed at TP?**
7. **What would the ideal alcohol and drug treatment service be like?**

Appendix 10: RSS Community Advisory Group terms of reference – A work in progress

Recovery Support Services Community Advisory Group Terms of Reference

Context
The Recovery Support Service (RSS) is a residential service for young people aged 16 to 25 who are experiencing significant AOD and co-occurring challenges. It is the residential arm of the Self Help Addiction Resource Centre (SHARC). This is a peer based organisation that values lived experience as an expertise.

The Community Advisory Group (CAG) was set up in to replace the Recovery Support Service Steering Committee towards the end of 2006. The CAG is a means for the service users of the Recovery Support Services to participate in decision making relating to this service. The Recovery Support Service Community Advisory Group is an essential part of SHARC Governance.

Values
We believe in getting help, giving help and helping yourself. Underpinning this belief are the values of inclusiveness, self determination and empowerment.   Communicating a message of hope to those new to recovery, the CAG is an opportunity for residents to take on a valued role.

RSS Mission
To model SHARC values in providing and maintaining opportunities for young people affected by addiction related problems to recover and participate in valued roles.

Objectives
 To realise its mission The Recovery Support Service pursues 8 objectives:
1. Provide a safe, supported drug free environment for residents and staff
2. Provide effective assessment and entry processes that maximize the opportunities for young people to enter the program
3. Provide effective recovery, planning and care coordination
4. Effectively facilitate positive RSS community spirit and unity
5. Provide effective programs and projects that maximise residents' opportunities to participate in valued roles
6. Provide leadership in demonstrating recovery values by 'walking the walk' and having integrity and humility in all our workplace relationships
7. Effectively integrate peer based approach with professional help
8. Participate as a team to realise our own potential in developing the skills and abilities to best bring the vision of hope to life.

Purpose of the Recovery Support Service CAG
• To assist in the direction of program improvements

1

Responsibilities
Members of the RSS CAG are responsible for:
1. Knowing the mission of the Recovery Support Service
2. Attending monthly meetings with a minimum attendance of 5 RSS service users.

SHARC is responsible for:
1. Recognising the RSS CAG as part of SHARC Governance
2. Ensuring the RSS CAG is adequately resourced to perform its role
3. Consulting with the Chair and one other member of the RSS CAG when another program of SHARC is in conflict with a RSS CAG project
4. Attendance of the CEO at CAG meetings at least twice yearly.

Meeting Procedures

1. For an RSS CAG meeting to proceed, a quorum of 5 RSS service users. If a quorum is not reached then the meeting is to be rescheduled.
2. RSS staff will give full consideration to advice and guidance provided by RSS CAG members. This guidance will be reviewed at the following RSS Direct Care Review. Feedback will be measured against organisational values and appropriate changes introduced. This process will be transparent and fed back to the RSS community at the next Monday morning Community meeting.
3. All meetings will be minuted and circulated to the RSS team. A summary of these minutes and the response to these minutes will be provided to the CEO and the Board.

Reporting

Reporting of RSS CAG activities will be included in the RSS manager's monthly report to the CEO and Board.

Positions

The RSS CAG will appoint a secretary and chairperson for the meeting. This is done at the start of the each CAG group.

2

Appendix 11: Dual Diagnosis Advisory Group flyer

Do want to be involved?

Have you

the experience of using alcohol + other drugs + mental health services?
used services in the eastern region of Melbourne?

Would you like to be

part of a regional committee?
reimbursed financially for your experiential contribution?

Want to know more?

ring ▉ on ▉ or ▉ on ▉

Alcohol & Drug
Strategy Group

Appendix 12 Eastern Region Dual Diagnosis Service User Advisory Council terms of reference – A work in progress

Dual Diagnosis Working Group Consumer/Service User Advisory Council

The Dual Diagnosis Working Group has been initiated to implement Strategic Action 2: Collaboration – Dual Diagnosis from the Eastern Metropolitan Region **Alcohol and Other Drugs Strategic Action Plan** April 2008 – December 2010.

The Dual Diagnosis Working Group has developed an action plan based on the five Service Delivery Outcomes as set out in the Department of Human Services policy document *Dual Diagnosis Key Directions and Priorities for Service Development* launched in May 2007. An addition to the plan relates to the inclusion of the Commonwealth funded Improved Services Projects creating six Action Plan Goals in total.

Goal 5 of the action plan as seen below relates to the development of a Dual Diagnosis Consumer engagement and participation strategy.

Eastern Metropolitan Region
AOD Strategy Dual Diagnosis Working Group
Action Plan 2008-2009

DHS Dual Diagnosis Action Plan Goal	Action	Person Coordinating	Key Deliverables	Time Line
5. Strengthen consumer and carer participation and feedback in training, service development and evaluation	• Compile consumer and carer rep. contact list for all organisations in EMR • Ensure consumer and carer representation at all working groups • Include carer/consumer experience/issues/information in all training programs	Consumer rep.		June 2009

	• Coordinate and facilitate consumer/carer evaluation of dual diagnosis message			

In consultation with the Association of Participating Service Users (APSU) the Dual Diagnosis Working Group has chosen to support the development of a Consumer Advisory Council linking directly with the AOD Strategy Dual Diagnosis Working group.

Aims

The aims of the Consumer Advisory Council are as following:

Support the activities of the Dual Diagnosis Working group in relation to implementation of the Action Plan Goals

Provision of feedback and consultation on all aspects of working group activities

Delegation of attendance at Dual Diagnosis working group meetings as required

Advice on the involvement of consumers in the dual diagnosis strategy

Evaluation of Dual Diagnosis activities using the Consumer Participation Model and similar models as a guide

Supporting the development of evidence based models relating to dual diagnosis treatments and interventions

Active participation in the development of protocols, policies and pathways documents

Development of activities that enhance consumer sensitive practice within AOD services

Facilitation and particpation

The facilitation of the group would be via an employed Service User representative but predominately made up of volunteer members

Reimbursement for participation in the group could be via?

The group would require a terms of reference with minutes from each meeting.

Appendix 13: FIT Peer Helper roles and responsibilities

FIT PEER HELPER ROLES AND RESPONSIBILITIES

The responsibilities of the peer helpers are:

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

The roles of the peer helper are to:

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

Appropriate activities for a peer helper whilst on placement

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

Appendix 14: FIT Peer Helper Training placement agreement

FIT PEER HELPER PLACEMENT AGREEMENT

The Association of Participating Service Users FIT Peer Helper Project

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

SUPERVISION:

The Peer Helper will have _____ supervision sessions with APSU staff.
The Peer Helper will have _____ supervision sessions with _____ from _____ (peer helper placement agency).
The Peer Helper will be under the direct supervision of _____ from_____ (peer helper placement agency) while completing practical peer helping placement hours.

If the Peer Helper breaches the placement agency's Code of Conduct or any other aspect of the placement agreement please contact: Ms Regina Brindle, Manager APSU, PH: (03) 9573 1736, E-mail: rbrindle@sharc.org.au

TASKS:

The Peer Helper will be involved in following tasks/activities during placement:

HOURS:

The Peer Helper will attend placement on _____, starting date_____, between the hours of _____, ending on _____ .

RESPONSIBILITIES:

The student is responsible to _____ at the agency of placement.
The student is responsible to APSU worker _____.
The student has signed the placement agency's Code of Conduct, YES/NO
The student has read the placement agency's relevant Policies & Procedures YES/NO

OCCUPATIONAL HEALTH AND SAFETY:

_____ will be responsible for public liability insurance for the Peer Helper
The Association of Participating Service Users will be responsible for insurance relating to the Peer Helpers behaviour whilst on placement at the above agency.

NAME OF PEER HELPER:
Contact Details:

Emergency Contact:

NAME OF AGENCY WORKER:
Contact Details;

NAME OF APSU WORKER:
Contact Details:

DATE:

SIGNED: _____ **Peer Helper**

_____ **Agency Representative**

_____ **APSU Worker**

Appendix 15: FIT Peer Helper Training evaluation form

Peer Helper Training Survey

Before the training, the rating that most closely matches my viewpoint:

Complete the column on the left by putting an X in the box that most closely matches your view about the statements in the centre of the page. Repeat this process for the column on the right. *Be sure to complete all the statements for the left column first.* Remember, there are no right or wrong answers. Thanks.

After the training started the rating that most closely matched my viewpoint:

Always Mostly Frequently Sometimes Never Uncertain Don't know

1. I feel supported & encouraged in my choice to become a peer helper.

2. I know what to do to help myself withstand pressure to act in ways that interfere with my well-being.

3. I have the knowledge about how to help other people in early recovery

4. I have the skills to assist other people in early recovery who come to me for help.

5. I feel confident to act as an advocate for peer helping.

6. I know how to refer someone whom I cannot help.

7. I know my limits & boundaries and when to refer someone who needs help.

8. I have an understanding of the resources available in the alcohol & other drugs service system.

9. I feel comfortable exploring my own ideas & coming to conclusions without being manipulated or coerced.

10. I feel empowered (have learned skills) to talk to program participants that have concerns about their substance use.

11. I accept there are different recovery styles and pathways

12. I can teach others how to show concern and offer support effectively.

13. This training course was fun.

14. My ability to understand and tune into the feelings of others is very good.

15. My ability to ask questions that help another person talk about what is of concern to them is very good.

16. The session I liked the most during the training was the session about…

_____
_____
_____
_____

16 (a) and the reason I liked that session the most was…

_____
_____
_____
_____

17. The session I like least during the training was the session about…

_____
_____
_____
_____

17. (a) and the reason I liked that session the least was…

_____
_____
_____
_____

2

Appendix 16: North Yarra Community Health peer worker position description

Position Description

NORTH YARRA COMMUNITY HEALTH

POSITION TITLE: CONSUMER REPRESENTATIVE – TREATMENT SERVICE USERS (TSU) PROJECT

Team: Drug Safety Services

Classification:

Reporting Arrangements: Manager Drug Safety Services via NSP Team Leader

Supervision: Nil

Superannuation: N/A

Employment Type: Casual

Other Benefits: Payment of "sitting fees"

Approved by: **On:**

1. Position Summary

Innerspace Drug Safety Services was officially opened in January 2009. The service was created by merging MINE Primary Needle & Syringe Program and Next Door Primary Health Unit which were previously co-located in adjacent shop fronts around the corner in Smith Street.

The Treatment Service Users (TSU) project seeks to engage a pharmacotherapy client who accesses the Innerspace pharmacotherapy service to work with clients, an external consultant facilitator and key staff of the service to advise NYCH on ways to improve the pharmacotherapy program. This would include suggestions for the redevelopment of the client charter of rights and responsibilities.

The Consumer Representative will engage other clients of the service so that their experiences and suggestions can be documented.

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2. Selection Criteria

2.1. Essential

2.1.1. Is a client of the Innerspace pharmacotherapy program

2.1.2. A willingness to consult other clients of Innerspace about the operation of the service

2.2. Desirable

- Understanding of cultural issues and ability to deliver services that are culturally sensitive
- A good understanding of Community Health, its principles and organisational forms
- Demonstrated commitment to community participation and ongoing engagement with consumers
- Demonstrated commitment to participating in the ongoing quality improvement activities of the agency
- Ability to work as part of a multi-disciplinary team
- Demonstrated capacity to manage competing priorities and to deliver high quality outcomes
- Well developed organisational and administrative skills
- Ability to speak a relevant community language would be highly regarded

3. Key Responsibilities

3.1. Engage other clients of Innerspace to determine their opinions on a range of topics related to the operation of the service

3.2. Work with the Manager of Drug Safety Services and NSP Team Leader to document client experiences and opinions

3.3. Respect and protect client confidentiality

3.4. Participate in relevant focus groups

3.5. Participate in meetings associated with the project

3.6. Participate in training for the project as directed

3.7. Other

- Understand and comply with the NYCH OH&S Policy and procedures and the legislative requirements relevant to this position
- At all times treat other staff with courtesy and respect
- Work in partnership with the community, clients and staff to achieve our vision
- Participate in relevant team meetings and staff development activities
- Maintain adequate records and provide reports as may be required
- Undertake other duties as directed which fall within the scope of the position and the skills of the position holder

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4. OTHER RELEVANT INFORMATION

This position description is approved by:

Occupant: ....Date:................

Team Leader: ....Date:................

Manager: ....Date:................

Appendix 17: Ovens & King peer worker position description

EXPRESSION OF INTEREST
POSITION TITLE:
Consumer Consultant
Making the Service Real –
Consumers for Quality Outcomes.

1st Floor
80-100 Ovens Street
Wangaratta 3677

P O Box 224
Wangaratta, 3676

P: 03 5723 2000
www.ovensandking.org.au

☑ **Are you interested in projects?**
☑ **Would you like to be involved in something new?**
☑ **Are you keen to work with other agencies?**
☑ **Are you passionate about the consumer / carer voice?**

Project Overview:

The project will engage a consumer/ advocate to assist with convening and facilitating regular groups of service consumers. The focus groups will provide a mechanism that gives insight and direction in the planning for the delivery of services and assist with the ongoing development and quality of the services provided to the community for pharmacotherapy and withdrawal services.

The consumer/ advocate will attend quarterly executive committee and Board of Governance meetings with an aim of providing feedback from the focus groups and participation strategic planning for Drug and Alcohol Services into the future.

Position Context:

While there is a role for consumer participation at a number of levels, the focus here is in developing and implementing consumer participation at the organisational level of drug treatment services and not in relation to individual treatment plans. Consumers will be given a voice to initiate changes that are relevant, timely and responsive to the needs of the service users. Ongoing evaluation of service users, service delivery, improvements and initiatives will be built into the quality cycle and reporting mechanisms.

Key Responsibilities

The key activities of this position will be:

- Involvement in sector training development and delivery
- Development and / or sourcing of consumer & carer resources relevant for the project deliverables.
- Participation in the review of current policies and procedures within the Ovens and King Community Health Service.

- Implement a Quality Feedback Cycle for services provided through Ovens and King Community Health Service.
- Advise organisation on service delivery improvement through recommendations from Consumer Focus Groups.

Employment Details:

Hours: 16 hours per fortnight (0.2 EFT) Flexible work conditions apply.

Employment conditions; Secondment from current employer is negotiable or a direct employment package with Ovens & King Community Health Service will be offered.

Supervision & Support; The position of consumer consultant will be supported by the Manager of Counselling and Support Services. The position will work closely and in partnership with the Alcohol and Other Drugs program.

The position is based in Wangaratta at Ovens & King Community Health Service.

Hourly rate: $22

Salary packaging: up to 30% as per agency policy.

Enquiries:

▮▮▮▮▮▮▮▮ Program Manager Counselling and Support Services
▮▮▮▮▮▮▮▮▮
▮▮▮▮▮▮▮▮▮▮▮

Appendix 18: MonashLink Improved Services Iniatitive steering committee consumer representative recruitment letter

MonashLink Community Health Services have a great opportunity for a person who has direct experience with alcohol and other drug and mental health. This is to participate in their steering committee. The Eastern Drug and Alcohol Service (EDAS) provide service delivery at MonashLink, as well as other sites in the east.

The Improved Service Initiatives Steering Committee informs the delivery of services to people who have mental health and alcohol and drug issues. The committee meets quarterly in 2009 and 2010, and there is a payment of $46 per meeting. Mentoring and training are available.

EDAS are mostly interested in people who have used their services. Even if you haven't used this service, still contact me anyway. My number is ▮▮▮▮▮▮▮ or ▮▮▮ ▮▮▮▮▮. This position will involve a simple selection process.

Regards

▮▮▮▮ ▮▮▮▮▮
Manager of the Association of Participating Service Users

Appendix 19: MonashLink Improved Services Iniatitive steering committee consumer representative interview letter

Name
Address

Date

Dear   ,

APSU is pleased that you are interested in becoming the Service User Representative for MonashLink's Improved Service Initiatives Steering Committee.

There is a selection process for this position. This will consist of a short informal interview with an APSU staff member and a MonashLink staff member. The following criteria will be addressed. That you:-

§ Have used Alcohol and other Drug Services (while it is preferable that you have used MonashLink's services, it is not essential)
§ Have experience and/or knowledge of Mental Health Services in Victoria
§ Are able to commit to the Steering Committee for one year (committee meets 4 times per year, some preparation and training will be required outside of meeting times)
§ Are able to clearly communicate your views to the Steering Committee, the organisation (MonashLink), and to other service users
§ Are able to represent how other service users may feel or think about certain issues and advocate on behalf of service users
§ Respect cultural and other differences

Your interview has been scheduled for   **00.00 pm Friday 6th March**
At MonashLink
7 Dunscombe Ave
Glen Waverley, 3150
Tel: 1300 552 509
Melway Ref 70 L2

Should you have any difficulty in making it to this appointment, please call me on ▮▮▮▮▮ or ▮▮ on ▮▮▮▮▮. Otherwise, I look forward to meeting you then.

Yours truly,

▮▮▮▮ ▮▮▮▮

Project Worker
Association of Participating Service Users (APSU)
▮▮▮▮▮▮

Appendix 20: MonashLink Improved Services Iniatitive steering committee consumer representative interview questions

MonashLink's Improved Service Initiatives Steering Committee

Interview questions for Service User Representative –Draft Only

Please tell us briefly what contact you have had with alcohol and other drug services

Please tell us what you know about Mental Health services in Victoria

Can you tell us about an experience you've had that required you to turn up regularly or be reliable eg voluntary/paid work, education, sporting group etc

Tell us what you think is difficult about communication

Do you have an example of a time when you had to communicate to someone very different to yourself, how did it go?

What are some of the issues people who use drugs face? How about people who have mental health issues?

Tell us what you understand about discrimination

Appendix 21: APSU steering committee terms of reference

ASSOCIATION OF PARTICIPATING SERVICE USERS
Steering Committee Terms of Reference

CONTEXT
The Association of Participating Service Users (APSU) is the advocacy arm of the Self Help Addiction Recovery Centre (SHARC). While SHARC is in the business of service delivery based on the core values of self-help and participation, APSU is the vehicle by which service users are able to more effectively influence the service system. The APSU Steering Committee comprises a majority membership of people with direct experience of substance use. It provides guidance to the staff of ASPU and is an essential part of the SHARC governance structure.

VALUES
We believe that those who come to us for help should be offered the opportunity to help others and to contribute to the development of our services. Underpinning this belief is the value of inclusiveness. The APSU Steering Committee is one vital way in which SHARC is able to foster service user participation with a view to improve the quality of its services.

APSU MISSION
Our mission is to enable service users of alcohol and other drug services to advocate for themselves, participate in service provision and influence policy and research that affects alcohol and other drug service users.

OBJECTIVES
To achieve its mission, APSU pursues three key objectives:
1. To work collaboratively with key stakeholders to increase service user participation in drug treatment and care providers systems.
2. To increase service user impact on relevant policy and research
3. To promote, encourage and assist service users in the development of consumer-run programs and activities.

PURPOSE OF THE APSU STEERING COMMITTEE
The APSU Steering Committee represents and advocates for the interests of people who use alcohol and other drug services, personally or by family association and/or friendship in Victoria by:
• providing advice, guidance and knowledge to the service manager
• participating in APSU activities as required
• assisting the manager to evaluate the effectiveness of the services, and
• providing input to strategic planning.

RESPONSIBILITES
Members of the APSU Steering Committee are responsible for:
• knowing APSU's mission
• attending Steering Committee meetings held every two months with a minimum attendance of 3 meetings a year
• making every reasonable effort to provide support to the service consistent with their ability and availability.
• providing leadership and direction; and
• providing conceptual input in the development of policies, programs and services.

Page 1

ASSOCIATION OF PARTICIPATING SERVICE USERS
Steering Committee Terms of Reference

SHARC is responsible for:
• recognising the APSU Steering Committee as part of SHARC Governance
• ensuring the APSU Steering Committee is adequately resourced to perform its role
• consulting with the Chair and one other member of the Steering Committee when another program of SHARC is in conflict with an APSU project, and
• attendance of the CEO at Steering Committee meetings at least twice annually

MEETING PROCEDURES
• For an APSU Steering Committee meeting to proceed, a quorum of one service provider and two service users is required. A representative of the APSU team must be present. If a quorum is not reached then the meeting is to be rescheduled.
• APSU staff will give full consideration to advice and guidance provided by Committee members.
• All meetings will be minuted and the minutes circulated to all APSU Committee members.

REPORTING
Reporting of APSU Steering Committee activities will be included in APSU's monthly board report.

POSITIONS
The APSU Steering Committee will appoint a chairperson for the term of one year, with election by the membership to be held in October.

MEMBERSHIP
The APSU Steering Committee will consist of nine members. Four members will be representing services relevant to advocacy and/alcohol and other drug and five members will comprise people with direct experience of substance use.

DISPUTE RESOLUTION
Any dispute that arises between members of the Steering Committee will be settled by the processes outlined in the SHARC Grievance Procedure. See Appendix.

PUBLICATIONS AND MEDIA RELEASE
Neither the Fund holder nor the Steering Committee will use the name of the other Party without previously having obtained the prior written consent of the other Party and the use of such name is subject to any such conditions attached to such consent.

RESIGNATION FROM THE COMMITTEE
All resignations from the APSU Steering Committee are to be in writing and addressed to the Chairperson.

Page 2

Appendix 22: Dual diagnosis experiential educator job description

Sessional Dual Diagnosis Experiential Educator

Job Description

POSITION CONTEXT

The Victorian Dual Diagnosis Initiative (VDDI) aims at developing the capability of all alcohol and other drug (AOD), and mental health treatment services to improve the health outcomes of people with a dual diagnosis.

In 2007 the Department of Human Services released the *Dual Diagnosis: Key directions and priorities for service development* document, which clearly states five service development outcomes for all mental health and AOD services, namely:

1. Dual diagnosis is systematically identified and responded to in a timely, evidence-based manner as core business in both mental health and alcohol and other drug services.

2. Staff in mental health and alcohol and other drug services are 'dual diagnosis capable', that is, they have the knowledge and skills necessary to identify and respond to dual diagnosis clients and advanced practitioners provide integrated assessment, treatment and recovery.

3. Specialist mental health and alcohol and other drug services establish effective partnerships and agreed mechanisms that support integrated assessment, treatment and recovery and ensure 'no wrong door' to treatment and care.

4. Outcomes and service quality for dual diagnosis clients are monitored and regularly reviewed.

5. Consumers and carers are involved in the planning and evaluation of service responses.

To assist services to achieve the above outcomes and as part of the capacity building, the VDDI Education and Training Unit (ETU) was developed and is auspiced by, St Vincent's Health. Under guidance of the ETU Manager, and in collaboration with other VDDI partners, the ETU has developed and implemented a state-wide dual diagnosis education and training strategy.

Part of this strategy has been the development and delivery of an on-line dual diagnosis course that is designed to assist the mental health (MH), alcohol and other drug (AOD) and Psychiatric Disability Rehabilitation and Support Services (PDRSS) workforces to become dual diagnosis capable.

This position has been developed by the Association of Participating Service Users (APSU) and the Victorian Mental Illness Awareness Council (VMIAC) and the ETU to ensure that the consumers "voice" is heard in the online dual diagnosis course.

BASIC JOB PURPOSE

The position, under guidance of the ETU staff and with support from APSU and VMIAC, will:

1. Develop small online training sessions;
2. Deliver those training sessions; and
3. Evaluate the effectiveness of the sessions.

QUALIFICATIONS

- Completed the Online Dual Diagnosis Course
- Completed the Online Facilitation Course
  Note: Successful applicants will be supported through these courses

KEY SELECTION CRITIERIA

- Experience of co-occurring alcohol and/or other drug use problems and mental ill health
- Have current capacity to carry out all required functions of the role.
- Commitment to completion of training units and delivery of at least three rounds of training
- Demonstrated ability to complete the online dual diagnosis course
- Demonstrated ability to complete the online facilitation course
- Demonstrate ability to communicate knowledge to a group

Accountability
Responsible to:

- APSU Coordinator;
- VMIAC Director; and
- VDDI ETU Manager

Appendix 23: Blueprint focus group flyer

Are you interested in **being paid $30.00**

to have your say on alcohol and drug treatment

services in Victoria

while being fed a **lovely lunch?**

Then come to a focus group and tell us

> ➢ What is GOOD about treatment
> ➢ What is NOT SO GOOD
> ➢ What might IMPROVE services

Come to TURNING POINT

54-62 GERTRUDE STREET
FITZROY
FROM 11.00 TILL 1.00

ON

WEDNESDAY 31ST OF JANUARY,2007

HAVE YOUR SAY AND HELP
PLAN FUTURE SERVICES

IF INTERESTED

Ring ▉▉▉▉ from APSU
on ▉▉▉▉

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