SARC briefs

Once you start having the conversation with people who use treatment services, once they begin to believe that you are genuinely listening to them, you won't be able to shut them up. Although the idea is scary there is nothing to be afraid of. You're talking about genuine partnership working in which both sides are clear what the purpose of treatment is. Other areas of health care did this years ago and we are only just catching up.

Consumer activist

Voices on Choices:

working towards consumer-led alcohol and drug treatment.

This study explores approaches towards consumer engagement in alcohol and drug treatment services. This has been slow to develop in Australia and other countries, like the UK, are further ahead and can offer useful lessons for promoting consumer activity specifically in Tasmania but also more broadly across Australia. The research was undertaken by the Social Action and Research Centre at Anglicare during 2009.

The research draws together information from interviews with over 40 UK and Australian based service users, drug and alcohol activists, government officials, policy makers and planners, academics and service providers. The research also involved a literature review and collating key policy and strategy documents.

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When it first came along it was seen as a flash in the pan; we'll ask them their views but they're all out of it anyway so they're not that interested. Services would say they've got user involvement just by having a suggestion box and to them that was enough. Now it's caught on. Services have been changed. The difference to when I first started six years ago and what is happening now in terms of levels of understanding and willingness to try different methods is like night and day.

Consumer development coordinator

What is consumer involvement in the alcohol and drug treatment sector?

Commonly consumer involvement is defined as the active participation of people who, because they have used services or are potential service users, can bring their knowledge and experience to contribute to the design, planning, delivery and evaluation of services. It is now an important concept in health and human services yet, despite many consumer initiatives in the mental health, women's health and disability sectors, consumer activity has been slow to develop in the drug and alcohol field. This is due to:

- the marginalisation of people who use substances which can be compounded by factors like mental health issues and homelessness;
- a perception that substance users are not so interested in or capable of making an informed contribution to the development of services as other consumers and their portrayal as impatient, manipulative, aggressive and undeserving;
- prohibition and the illicit nature of much drug use which makes it difficult to recruit to consumer initiatives because of the fear of identifying with illegal activities; and
- difficulties in dealing with the diversity of those using substances. For example, opiate injectors will have different issues and concerns to those using cannabis or alcohol.

These factors mean that implementing consumer involvement in the substance use field is complex and challenging.

Research findings

Key finding 1: A proliferation of consumer activity in the UK

Consumer involvement in health and social care provision in the UK has been a statutory requirement since 2002 and has been promoted and resourced in the drug treatment sector and, to a lesser extent, in the alcohol treatment sector at a national level. This has led to a proliferation of diverse consumer activity where every service now has a consumer engagement policy and locally most areas have active consumers involved in designing, purchasing and evaluating services. It is now generally accepted that consumer involvement has the ability to enhance service delivery as well as instigate change and reform in the sector. It is also seen as improving retention in treatment, promoting higher levels of client satisfaction, reducing contact with the criminal justice system and increasing entry into education, training and employment.

Key finding 2: Best practice models

There is no single best practice model in the UK but rather a spectrum of mechanisms and approaches for initiating, promoting and sustaining consumer involvement, each with its own challenges and difficulties. The research documents this range, which includes promoting involvement at an individual treatment level, consultation and representation models and peer research. It also documents the involvement of consumers in producing information and resources about services and treatment options, in the monitoring and inspection of service provision, in training and education, in staff recruitment, in volunteer work and employment and in setting up and operating consumer-led services. It describes the workings of national government sponsored models of consumer involvement, strategic approaches which aim to support the development of involvement activities in local services, mechanisms adopted by service delivery organisations and the establishment and sustainment of consumer groups.

Key finding 3: Implementing effective consumer involvement

There are a number of challenges involved in developing and implementing effective consumer involvement. These include the perceived characteristics of people who use services and the attitudes of both professionals and consumers. There are strategic and structural difficulties like inadequate resourcing and unclear aims, goals and responsibilities. These difficulties have been compounded in the UK by a divided consumer involvement movement with no strong national consumer voice or formally constituted consumer-led organisation and the lack of a comprehensive evidence base about the efficacy of consumer involvement in this field. These challenges mean that across the UK there are local areas where implementation has been patchy and tokenistic and where the principle of consumer involvement is taking a long time to influence culture and practice in the drug and alcohol treatment field. A key factor in the lack of consistency nationally is seen to be the absence of specific guidance about 'how to do' consumer involvement as well as a failure to systematically monitor implementation.

Key finding 4: The Australian context

In Australia, although consumer participation in drug and alcohol treatment services is broadly endorsed by government, consumer participation has not been institutionalised and there is no national framework or approach to guide and support implementation at a state or territory level. This has led to a situation where although many services operate 'low degree' consumer participation based on a consultation approach there is little higher degree involvement with consumers involved in real decision-making. Tasmania has been described as 'ground zero'

> ***In drug services they think they know how to treat people best and they don't take kindly to you going in and giving them assistance on how to change things to suit the service user better. But this year every single service which has a service level agreement or any contract has a set of seven key performance indicators or targets which they have to feed back on every quarter about what they're doing with user involvement. We've never had it as contractual and performance related before. Everything else is performance related so why shouldn't user involvement be as well? This will make user involvement a lot more robust.***
>
> Consumer group

> ***Some areas are phenomenally good and others are weak but you will never have an area where it doesn't happen at all. All it takes is a couple of local champions and you can do really important and exciting work. In those areas where it exists and where it's working well it's completely transforming drug treatment systems and making them totally responsive to what people who use the system want and need.***
>
> Consumer activist

in terms of consumer participation with no consumer-led organisation and only a very recent injection of government funding to explore what models might be appropriate.

Key finding 5: Lessons for Australia

The research identifies a number of key messages for Australia in developing consumer participation in the alcohol and drug sector. They are that:

- consumer involvement requires nurturing by government. A national approach underpinned by adequate resourcing is critical to achieving consistency and compliance. This should be reinforced through standards, accreditation and regulatory and review processes and integrated into service contracts and tendering processes with specific guidance about how to implement it. Consumer engagement mechanisms should become a key quality indicator for service providers and embedded into service provision as a core part of service delivery activity.
- there is no 'one size fits all' model. Any approach should be evolutionary and tailored to particular consumer cohorts and treatment environments whilst offering choice in involvement opportunities.
- the spirit in which consumer involvement is implemented is just as important as the model which is used and requires both leadership from consumers as well as professional champions to promote it.
- staff and consumer attitudes are a key determinant and require a long term process of cultural change reinforced through awareness raising and training, supervision and mentoring.
- continuing success and the sustainability of involvement initiatives depend on a strong evidence base and the documentation of good practice.

Anglicare recommends:

- that the National Drug Strategy and state and territory drug and alcohol strategies incorporate the principles of and outcome indicators for consumer participation.
- that governments ensure that a requirement to involve consumers together with key performance indicators and targets is integrated into all alcohol and drug treatment service funding agreements and tendering processes and is systematically monitored and reviewed.
- that state and territory governments invest in supporting treatment services, particularly in the community service sector, to access appropriate training and skill development around consumer participation activities for providers and consumers.
- that education or training initiatives for AOD clinicians and service providers include the consumer perspective and the value of consumer participation as well as examples of good practice.
- that any consumer participation activity pro-actively considers pathways for consumers into volunteer work and employment and that recruitment processes in the AOD sector ensure that the lived experience of substance dependence should not operate as a barrier to employment.

Case Study 1: A national consumer involvement model

The National Treatment Agency for Substance Use (NTA), set up in 2001 to oversee the development of drug treatment in England, has always seen the involvement of consumers as fundamental to improving treatment. It established a national, regional and local structure which has operated as a catalyst for consumer involvement work across the country. This entails:

- regional consumer forums to bring representatives from local areas together for information sharing, consultation and reporting;
- integrating consumer involvement into NTA activities at every level including having a representative on the Board;
- issuing a policy and guidance for local areas about consumer and carer involvement activities; and
- establishing performance indicators for user involvement so that each local area is assessed against six key criteria for user involvement.

The approach has led to firmly establishing consumer involvement in the English drug treatment system where it has become a standard and essential component of provision and accompanied by improvements in treatment.

> ***We have formally worked with consumer reps on contractual development and tender processes. They are able to get to the bottom line when assessing new services and forecast the usage of new services. They are also a great indicator of what is missing and have the capacity to act formally as regulators and are very good at assessing risk – a core function of any regulatory process. Their contribution always adds value and in a perfect world they would be the commissioners[1] rather than ourselves.***
>
> Service commissioner

1 Commissioning is the process of specifying, securing and monitoring services to meet needs.

Case Study 2: A national approach in Scotland

Here the predominant approach has been based on peer research focusing on improving service quality. This has entailed recruiting groups of 6-10 stable consumers and training them in involvement work, survey interview techniques, computing and presentation skills. The research groups are then contracted by planners, funders and services to undertake research including needs assessments and service user consultations. They have also devised their own research and consultations about specific issues. They have been involved in the development of drug quality standards with the Scottish Government and in the inspection teams inspecting drug and alcohol services. Groups are supported by development officers and a consumer involvement handbook.

Establishing and maintaining this model in an urban area was estimated to cost the equivalent of approximately $100,000 per annum. This model is able to produce a representative rather than anecdotal perspective of consumer experiences and a firm basis to argue for service changes. In the process it builds self esteem and skills which enable participants to move on to education, training and employment. The model also retains an independence from services.

Case Study 3: Consumer involvement in a community service organisation

Addaction operates over 70 services for substance users across England but despite its size it has not lost touch with its desire to integrate consumer involvement into service development and delivery. It has established:

- an organisation-wide consumer involvement strategy giving service users significant influence over the organisation's policy and strategic direction;
- a Service User Involvement Coordinator who is an ex-service user and activist responsible for evaluating the organisation's involvement activities, engaging all services in a debate about how to improve them and promoting the cultural change required to achieve this;
- a National Forum made up of current, stable consumers and providing representation on the clinical governance working group and with directors and trustees. Competition to participate in the Forum is vigorous and requires consumers to go through a rigorous selection process;

- 'peer champions' in local services to advise on communications, consultation and playing an important role in welcoming new clients; and
- training for consumers and staff on the role and importance of consumer engagement.

There is now work to develop the Forum so that its representatives will regularly attend Board meetings.

Case Study 4: Promoting consumer involvement in local services

The London Borough of Croydon has developed a framework for involvement in drug and alcohol services in the borough. Each service provider is encouraged to:

- outline a consumer involvement strategy and action plan;
- identify a nominated person to take the lead on involvement issues, act as a mentor to consumer representatives and ensure their involvement in service development;
- implement a range of methods of engagement from suggestion boxes to establishing consumer groups;
- prepare an annual report on these activities; and
- feed the views from service users into the policy and planning processes for local areas.

Additional support is provided by a Service User Involvement Coordinator responsible for raising the profile of involvement, training and support services. The model ensures that a range of views are heard through a spectrum of consultation mechanisms and that attention is being paid to creating a pathway for those involved as representatives into volunteer work, training and paid employment. One of the most significant consequences of the model has been the establishment of a peer-led support service in the borough.

Case Study 5: Consumer groups

A drug consumer group established in 2002 in south east England is now an independent charity with three full time staff. It runs peer education workshops and provides peer support and advocacy, produces information and resources, delivers training to consumers and providers, runs a volunteer program and is fully involved in the planning and commissioning process for services locally. It has worked at a national level to set up other

Social Action and Research Centre (SARC)

Anglicare's SARC team works with low income Tasmanians to identify the structural barriers that impact most severely on their lives. The Centre pursues policy change on these issues at a State and Federal level.

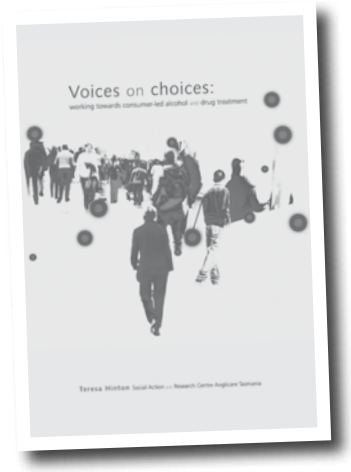
consumer groups across the country and now holds a number of training and user involvement contracts. Most recently it has been commissioned to develop consumer involvement activities in drug and alcohol treatment in prisons.

An alcohol consumer group in north east England set up by a recovering alcoholic has grown into a large alcohol specific peer-led service operating from four different buildings with 15 staff. It is now commissioned by the local Health Trust to provide a network of support groups for those with alcohol problems as an alternative to the 12-step approach.

A drug consumer group in one London borough set up in 2005 is now contracted to run a weekend peer-led social club providing out-of-hours support and social activity to current and ex-drug users. It is supported by 65 volunteers who are both scripted and abstinent service users. It has been instrumental in developing training packages offering the key skills required for users to move into education and employment.

For more information

The full report, *Voices on Choices: working towards consumer-led alcohol and drug treatment* by Teresa Hinton, is published by the Social Action and Research Centre at Anglicare Tasmania. It is available by calling 6213 3555. It can be downloaded at **www.anglicare-tas.org**



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