Voices on choices:
working towards consumer-led alcohol and drug treatment

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The research findings, conclusions and recommendations of this report are those of Anglicare and should not be attributed to any members of the Advisory Group. Any errors in the report are the responsibility of the author.

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Glossary of Terms

Alcohol Concern is a national agency which campaigns for effective alcohol policy and improved services for people whose lives are affected by alcohol-related problems across the UK.

Australian Injecting and Illicit Drug Users League (AIVL) is the 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.

Care Commission regulates all adult, child and independent healthcare services in Scotland.

Care Quality Commission is the independent regulator of health and social care in England regulating care provided by the National Health Service, local authorities, private companies and community sector organisations.

Commissioning is the process utilised in the UK through which health service and local authority agencies identify local needs for services and assess them against the available public and private sector provision. Priorities are decided and services are purchased from the most appropriate providers through contracts and service agreements. As part of the commissioning process services are subject to regular evaluation.

Drug Action Teams (DATs) are local partnerships responsible for developing and delivering drug strategies to meet local needs. In some areas DATs have become Drug and Alcohol Action Teams (DAATs) which also have responsibility for alcohol strategy.

Department of Health (DoH) exists to improve the health and wellbeing of people in England.

General Medical Council registers doctors to practise medicine in the UK. Its purpose is to protect, promote and maintain the health and safety of the public by ensuring proper standards in the practice of medicine.

Home Office is the United Kingdom government department in charge of domestic affairs including immigration control, security and order, and the police.

Joint Commissioning is the process in which two or more commissioning agents act together to co-ordinate their commissioning, taking joint responsibility for the translation of strategy into action.

Local authorities are bodies empowered and required by Acts of Parliament to carry out the local government of their areas. The Council is the final decision-making body within a local authority. They deliver services through leadership which is democratically accountable to local communities.

National Health Service (NHS) is the publicly funded healthcare system in Britain.

National Treatment Agency for Substance Use (NTA) is a special health authority which manages the commissioning and delivery of drug treatment services in England.

Northern Ireland Assembly is the devolved elected representative body set up in 1999 with limited powers to make laws for Northern Ireland.

Primary Care Trusts (PCTs) are free-standing statutory bodies within the NHS with responsibility for the health care needs of their local community. They receive budgets from the Department of Health and commission and provide primary health care and community services as well as commissioning hospital services for patients.

Putting People First is a ministerial concordat which establishes collaboration between central and local government, providers and the regulator to guide the transformation of adult social care and support the UK Government's commitment to independent living for all adults.

Royal College of General Practitioners is the UK's professional membership body for family doctors.

Scottish Drugs Forum is a national non-government drugs policy and information agency working in partnership with others to co-ordinate effective responses to drug use in Scotland.

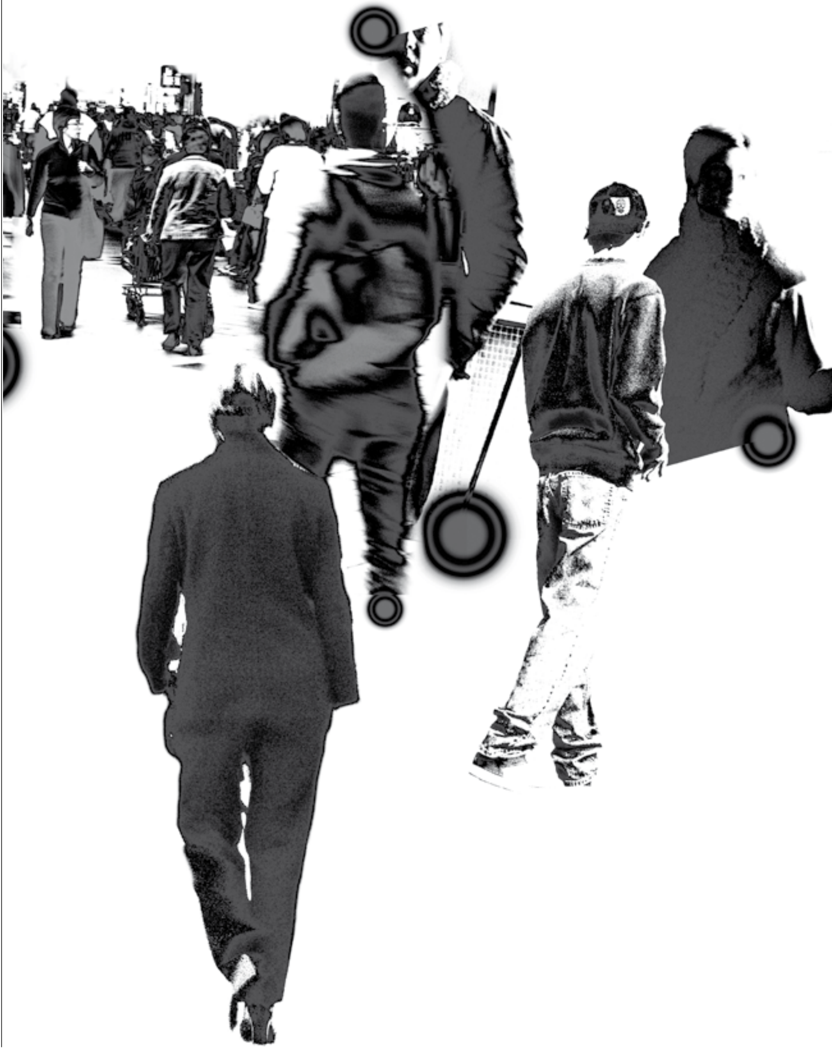
Scottish Executive is the executive arm of the devolved government of Scotland.

Social Work Inspection Agency is an independent government agency formed to improve the quality of social work services across Scotland.

Supporting People is a UK government programme which helps vulnerable people to live independently and keep their social housing tenancies. It is a grant programme administered through partnerships with Housing, Health, Social Services and Probation and largely delivered by community sector organisations.

Treatment Effectiveness Strategy launched in 2005 aims to improve retention and treatment completion, maintain improvements in waiting times and help service users reintegrate into the community by providing help with education, employment and housing.

Welsh Assembly is the devolved government for Wales with the power to introduce secondary legislation in areas such as health and education in Wales.



Abbreviations

AA	Alcoholics Anonymous
AIHW	Australian Institute of Health and Welfare
AIVL	Australian Injecting and Illicit Drug Users League
AOD	Alcohol and Drugs
APSU	Association for Participating Service Users, Victoria
ATDC	Alcohol, Tobacco and other Drugs Council of Tasmania
ATOD	Alcohol, tobacco and other drugs
BADSUF	Bournemouth Alcohol and Drug Services User Forum
BBV	Blood Bourne Virus
CAHMA	Canberra Alliance for Harm Minimisation and Advocacy
CAST	Community Alcohol Support Team
CSO	Community Service Organisation
DAT	Drug Action Team
DHHS	Department of Health and Human Services, Tasmania
DoH	Department of Health, UK
DoHA	Department of Health and Ageing, Australia
EDACT	Eastern Drug and Alcohol Coordination Team, Belfast
IDTS	Integrated Drug Treatment System
ISA	Independent Safeguarding Authority, England.
KPI	Key Performance Indicator
NDUDA	National Drug User Development Agency
NERAF	North East Regional Alcohol Forum
NHS	National Health Service
NICE	National Institute for Clinical Excellence
NTA	National Treatment Agency for Substance Use, England
NUAA	New South Wales Users & Aids Association
NUN	National Users Network
NVQ	National Vocational Qualification
QuIHN	Queensland Injectors Health Network
OUT	Oxfordshire User Team
PAMS	Pharmacotherapy Medication and Support Service
PCT	Primary Care Trust
PLUG	Croydon Peer Led User Group
RCGP	Royal College of General Practitioners
RUF	Reading User Forum
SAVIVE	South Australian Voice for IV Education
SUDRG	Kensington and Chelsea Service Users Drug Reference Group
SURG	Service User Representation Group, Croydon.
TasCAHRD	Tasmanian Council on AIDS, Hepatitis and Related Diseases
TUHSL	Tasmanian Users' Health and Support League
UK	United Kingdom
WASUA	Western Australian Substance Users Association

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Executive Summary and Recommendations

Hearing and responding to the voice of the consumer has become a key principle in the delivery of health and social welfare services in Australia and is now commonplace in fields such as mental health, disability and cancer treatment. However developments have been slower in the alcohol and drug treatment sector which lacks mechanisms to involve consumers. Other countries are further ahead and, although they might operate with different policy and substance use environments, potentially offer useful lessons for promoting consumer activity across Australia.

This report is based on an exploration of UK models of consumer engagement in alcohol and drug treatment services which was undertaken over a six month period in 2009. It involved a literature review, the collation of policy and strategy documents and interviews with key informants including government officials, policy makers and planners, academics, service providers, service users and activists. Traditionally services have involved consumers through consulting directly with them or their representatives about the services they receive. The emphasis in this report is on forms of consumer participation that go beyond consultation and which actively promote consumer-led provision and involve people who use services in their design and delivery.

The research found that:

- 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 many areas have active consumer groups involved in designing, purchasing and evaluating services. It is now generally accepted that consumer involvement has the ability to enhance service delivery and 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.
- There is no single best practice model 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 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.
- 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, strategic and structural difficulties like inadequate resourcing, unclear aims, goals and responsibilities, 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 the culture and practice in the drug and alcohol treatment field. A key factor in the lack of consistency nationally is seen as the absence of specific guidance about ‘how to do’ consumer involvement, baseline standards and a failure to systematically monitor implementation.

- 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. Tasmania has been described as 'ground zero' 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.

- The research identifies a number of key messages for Australia in developing consumer participation in the alcohol and drug sector. They are:
    - 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, 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, training, supervision and mentoring;
    - continuing success and the sustainability of involvement initiatives depend on a strong evidence base and the documentation of good practice.

Recommendations

Policy and strategy

Recommendation 1:
That the National Drug Strategy incorporate the principles of and outcome indicators for consumer participation.

Recommendation 2:
That the principles of and outcome indicators for consumer participation in treatment services be incorporated into the Tasmanian Drug and Alcohol Strategies.

Recommendation 3:
That the Australian and Tasmanian 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.

Recommendation 4:
That the Tasmanian Department of Health and Human Services ensure that any consumer participation framework developed through the Future Directions[1] process include an implementation and action plan, targets, review dates and evaluation processes.

Recommendation 5:
That the Tasmanian Department of Health and Human Services ensures that the portrayal of Tasmanians with substance dependence is underpinned by the principles of respect in all government materials and that the implementation of this is routinely monitored in order to build a consumer culture.

Funding

Recommendation 6:
That alcohol and drug service funding bodies include additional funding to support consumer participation initiatives and their evaluation; for example the reimbursement of costs to consumers.

Building capacity

Recommendation 7:
That the Tasmanian Department of Health and Human Services strengthen consumer engagement with the Tasmania health and human service system by establishing a body to represent consumers and the community, to support engagement activities and to strengthen consumer networks and organisations.

Recommendation 8:
That the Tasmanian Department of Health and Human Services invest in supporting treatment services, particularly in the CSO sector, to access appropriate training and skill development around consumer participation activities for providers and consumers.

Recommendation 9:
That education and training initiatives for AOD clinicians and service providers include the consumer perspective, information about the value of consumer participation and examples of good practice approaches.

Recommendation 10:
That any consumer participation activity pro-actively considers pathways for consumers into volunteer work and employment

Recommendation 11:
That recruitment processes in the ATOD sector ensure that the lived experience of substance dependence does not operate as a barrier to employment.

Monitoring and evaluation

Recommendation 12:
That consumer engagement activities at State and Federal levels are fully documented, evaluated and publicly disseminated in order to improve the evidence base for consumer participation activity and the sharing of good practice.

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[1] Future Directions refers to Tasmania's five year strategic plan for alcohol, tobacco and other drug services (DHHS 2008).

1. Introduction

Involving consumers in the planning, development and delivery of health and human services is now an important concept in health and social welfare policy and practice. The benefits both in terms of outcomes for consumers and in providing better quality services are widely praised. Yet, despite this trend and significant consumer activity and initiatives in the mental health, women's health and disability sectors, those using alcohol and drug treatment services have received less attention and involvement activities have been slow to develop in this field. This is true across Australia which has yet to provide a consistent framework for the voices of consumers of drug and alcohol services to be heard and used to empower individuals and improve treatment services. Tasmania is particularly poorly served and unlike most other jurisdictions, has no consumer-led organisation to push involvement activities. The lack of any mechanism to involve consumers in the drug and alcohol field in Tasmania has been identified in the five year plan for alcohol, tobacco and other drug (ATOD) services (DHHS 2008) and there is now a commitment to establish a consumer participation framework during 2010.

Internationally, other countries including the United Kingdom, Canada, the United States and New Zealand appear to be further ahead in promoting consumer involvement activities in this field. This suggests that important lessons might be learnt from their experiences. In response to this situation this research explores the situation in the UK where there is now a strong consumer involvement movement. It maps the growth and current status of consumer involvement activities in drug and alcohol services, explores the issues and trends and draws some conclusions about what this might mean for developments in Australia.

The research was carried out by the Social Action and Research Centre over a six month period from July 2009 to January 2010.

1.1 Language

A consensus about what language to use to refer to people who have problems with alcohol and/or drugs and generally to refer to people who use or might use treatment services does not exist. The terminology that is used reflects different ways of conceptualising the relationship between those who use services and those who provide them (McLaughlin 2008) and highlights ideological divisions (Hunt et al 2010) which can perpetuate negative stereotypes, discrimination and exclusion.

The term 'addict' is associated with the disease model and the 12-step movement where alcohol and drug users are seen as drug dependent, suffering from a life-long disease and the victims of addiction. Then there are a range of terms like 'drug abuser' or 'substance misuser' and 'junkie' all of which have negative connotations and which many substance users would find offensive. These terms exclude those who see their drug taking as non-dependent, as recreational and as unproblematic. The terms 'junkie' and 'addict' have been derogatory words in our culture and stopping using drugs is described as 'getting clean' implying drug users are 'dirty'. However there is a move to reclaim the term junkie (in the same way that the word 'queer' was reclaimed by the gay rights movement) in the Dutch Junkie Bond[2].

This complexity in defining a suitable language requires an ongoing sensitivity to different perspectives and preferences and, as a recent study highlighted, the words used to describe someone struggling with alcoholism or drug addiction may significantly alter the attitudes of health professionals (Kelly 2010). Answers given by over 500 health professionals to the difficulties faced by a hypothetical patient were surveyed. They varied depending on whether the patient was described as a 'substance abuser' or 'having a substance use disorder' with the former evoking more punitive attitudes. Many affected individuals do not seek treatment and a major reason for not seeking treatment which is commonly cited is the stigma against addiction problems. Neither are terms like 'abuser' used in other clinical areas; for example individuals with eating related problems are referred to as having an 'eating disorder' and not as 'food abusers'.

People who use services can be seen as citizens with rights, consumers with choices and/or

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[2] The Dutch Junkie Bonds or 'addicts' unions' developed during the 1980s in the Netherlands and were involved in harm reduction work and policy, planning and research.

as co-providers of services. In Australia those who use health and human services are called 'consumers'. This emphasizes a rights based approach where service users are rational beings who can exercise choice. In the UK the term used is 'service user'. This is considered to be the most neutral term but can have negative connotations of being exploitative and also neglecting those unable or unwilling to access services. In the user involvement world both countries have rejected the term 'client' which implies someone in need of help because they lack the ability or capacity to help themselves. The term 'experts by experience' is gaining recognition as it claims specialist knowledge and a relationship of equals which narrows the gap between providers and users. It can also include those who need but who do not use services.

Throughout this report the term 'service user' and 'user involvement' will be used in relation to discussions about the UK situation and 'consumer' and 'consumer participation' in discussions about the situation in Australia.

1.2 Defining User Involvement

In the UK and in Australia user involvement has become the new mantra in the public sector and a central concept in the reform and modernisation of services. Yet although the concept of involvement may be simple there is a complexity in motivations, models and implementation which can be difficult to disentangle in order to establish what it actually means. This makes it a vague term where the meaning and purpose often remain unclear and where providers and users understand and practice it in different ways.

User involvement can encompass many activities from participation in decision making and representation in policy forums, through to consultation and information giving, paid employment and peer-led services, delivering education and training, self help and mutual support groups and involvement in individual treatment decisions. It can be seen as a democratic right and an ethical requirement. There are top down and bottom up approaches where motivations differ. For example governments are concerned with efficiency and accountability and user involvement is seen as a means to reduce costs, enhance accountability, improve quality and increase user satisfaction. On the other hand the public concern is to improve service quality and promote citizen rights so user involvement can become an end in itself, irrespective of tangible outcomes (Patterson et al 2008).

Commonly, user 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. User involvement is implemented at three levels: at the individual level by involving people in their own treatment, at the service level through involvement in improving the services they use and lastly at the strategic level through involvement in wider policy and planning decisions about the treatment sector.

1.3 User Involvement in the Alcohol and Drug Treatment Sector

Although the principles underpinning user involvement in alcohol and drug services do not differ from those in other parts of the health or social services sector there are some aspects of these services and their users which make it especially difficult to implement effective user involvement mechanisms. This means user involvement has been relatively slow to develop in this field.

Firstly alcohol and drug users can be marginalised due to their substance use and due to complicating factors like homelessness or mental health issues which distance them from mainstream public structures and services. The tendency to scapegoat people who use drugs and alcohol which is accentuated by the illicit nature of much drug use can isolate and stigmatise. Secondly, in addition, they may be seen as not so interested in or capable of making an informed contribution to the development of services as other consumers. They can be portrayed as impatient, manipulative, aggressive and undeserving (Fischer et al. 2008). This means that individuals may be blamed for their condition and made to feel that they do not deserve to be treated well or even to get a service at all. They can also be fearful of being denied treatment if they are seen as difficult clients. Thirdly prohibition and the illicit nature of much drug use make it difficult to recruit to any user involvement activities because of the fear of identifying with illegal activities.

Finally, there are difficulties in dealing with the diversity of those using the alcohol and drug treatment sector. Existing user-led organisations tend to represent one type of consumer with particular needs which are not necessarily shared by others. For instance, opiate injectors will have different issues and concerns to those using cocaine, cannabis or dance drugs. Injecting drug users have in many respects led the user involvement movement both in the UK and in Australia and this has marginalised the voices of other drug users.

All these factors mean that implementing user involvement in the substance use field is unlikely to be straightforward.

1.4 The Prevalence of Alcohol and Drug Use

An evaluation of the Australian National Drug Strategy (Siggins Miller 2009) draws together comparative figures for alcohol and drug consumption internationally. Data from the Commission for Distilled Spirits, cited by the Australian Institute of Health and Welfare (AIHW 2007), shows that Australia ranks 22nd for alcohol consumption in the list of the top 45 countries based on per capita consumption of total pure alcohol. This means it has similar levels of consumption to Canada, New Zealand and the USA and is lower than the UK.

It is harder to make international comparisons of the use of illicit drugs because the data from which figures are derived use different sampling methods, measurement instruments and time periods. However, as Table 1 indicates, Australia has the highest prevalence of the use of ecstasy and also ranks highly in amphetamine use. Cannabis use is less than in New Zealand, the USA and Canada and the reported prevalence of cocaine use is lower than these countries. Prevalence rates for opioid use are also lower than in the UK and the USA.

What about problematic substance use? In the UK it is estimated that there are 404,884 problem drug users; defined as those people using opiates and/or crack cocaine. Approaching a hundred and forty eight thousand (147,855) of these are injecting drug users (UKFP 2009). In addition 26% of adults have an alcohol use disorder (38% of men and 16% of women). This is equivalent to approximately 8.2 million people in England (House of Commons 2006). It is also estimated that approximately 3 million people in Britain aged 16-74 are alcohol dependent (IAS 2008).

Table 1:

Annual prevalence of illicit drug use as a percentage of population aged 15-64 years

Nation	Ecstasy	Amphetamines	Cannabis	Cocaine	Opiates
Australia	4.4	2.9	11.4	2.0	0.5
New Zealand	2.6	2.3	13.3	0.8	0.4
England & Wales	1.8	1.3	8.2	2.6	0.9*
USA	1.0	1.6	12.2	3.0	0.6
Canada	1.3	1.0	17.0	2.3	0.3

* United Kingdom
Source: United Nations Office on Drugs and Crime 2008. World Drug Report 2008. Vienna: UNODC, 273-80

In Australia it is estimated that 31% of men and 22% of women (a total of 35.4% of the population) are drinking at risky or high risk levels for alcohol related harm (AIHW 2007). Fifteen per cent of the Australian population aged 14 years and over had used illicit drugs at least once in the previous 12 months (AIHW 2007), with cannabis being the most common. Among the treatment population the most common principal drug of concern in treatment was alcohol (37%), followed by cannabis (23%), heroin (17%) and methamphetamine (11%).

In Tasmania indicators of drug use (Bruno et al. 2007) show that alcohol consumption is high compared to national figures and the state has higher rates of risky drinking than elsewhere with 40.1% of the population aged over 14 years risking alcohol-related harm in the short term compared to 35.4% nationally (AIHW 2007). Approximately one third of episodes in treatment services relate to people with alcohol as their primary problem drug. Overall illicit drug use in Tasmania mirrors the national average and the numbers of people who self-report ever using illicit drugs is proportionate to that of other jurisdictions. Use of cannabis, of ecstasy and of crystalline methamphetamine (or 'ice') is comparable to the prevalence nationally. However there are some important differences:

- use of pharmaceutical products such as pain killers and psycho-stimulants is proportionally higher in Tasmania than elsewhere (Bruno 2004);
- use of heroin is lower than other jurisdictions. Less than 1% of Tasmanians over the age of 14 reported use of heroin or other opioids for non medical purposes in the previous year;
- amongst injecting drug users there is a higher rate of diverted pharmaceutical opioids than in other jurisdictions. In the north and north-west this primarily relates to diverted morphine use. In the south, morphine, methadone and oxycodone are consumed. The injection of methadone syrup and illicit physeptone is recorded as the highest in Australia;
- use of cocaine is lower than elsewhere; and
- accidental death due to opioid use is significantly higher in Tasmania, with an average of 53.7 per million people compared to the national average of 32.5 per million. This is accompanied by dispensing rates of opioids which are 300% the national rate.

Treatment data for Tasmania (AIHW 2007) shows that alcohol is the drug most commonly involved in treatment episodes (38%) followed by cannabis (34%), amphetamines (12%) and opioids (11%). Morphine accounts for 5% of treatment episodes. The most common form of treatment provided is counselling (62% of episodes) followed by information and education (17%) and rehabilitation (8%). Six hundred people are receiving opioid maintenance pharmacotherapy in Tasmania. Interestingly a greater proportion of treatment services here are devoted to individuals where cannabis is their principal problem drug (approximately one third of all episodes) than in services nationally (where it is approximately one quarter).

1.5 Research Aims and Methods

The research aimed to explore and describe UK experiences in developing user involvement in alcohol and drug treatment services and consider what this might mean for developments in Australia. In particular it aimed to provide service users, service providers and policy makers with practical ideas about how to implement strategies for user involvement. The research objectives were to:

- explore models of consumer participation and their implementation in alcohol and drug services in the UK;

- outline what lessons can be learnt for progressing participation and implementation strategies in Australia; and

- make recommendations about how to progress consumer participation in the alcohol and other drugs sector in Tasmania.

The research included a number of stages:

- **identifying key organisations and individuals in the UK as informants**. This proceeded using a snow balling technique whereby one informant would recommend others. The aim was to identify those individuals and organisations who could represent and describe the range of models and approaches towards user involvement in the drug and alcohol field. It resulted in identifying a mix of people who had been instrumental in planning, developing, implementing and operating particular approaches to user involvement across the UK.

- **interviews with key informants** either face-to-face or on the telephone. In total 34 interviews were conducted using a semi-structured interview schedule. Interviews lasted from 30 minutes to over an hour and the schedule covered the nature of the user involvement model, its origins and development and difficulties and successes. It also asked for people's views about user involvement more generally and how they saw it developing in the future. Interviewees included drug and alcohol activists, government officials, academics, people appointed to take a lead on service user involvement, commissioners[3], service providers and service users. The researcher also talked in some detail to eight service user groups about the achievements and difficulties of setting up and sustaining user-led organisations.

- **a literature review** and collation of background policy documentation. This was undertaken to provide a backdrop to the research, to locate the major trends and debates and to draw on any mapping exercises of user involvement activity.

- **informal contact** and conversations. The researcher attended a number of events including conferences and service user forums. These provided opportunities to talk more informally with stakeholders with an interest in user involvement activities, including current and ex service users.

- **interviews with key stakeholders in Australia.** This involved arranging telephone interviews with the Australian Injecting and Illicit Drug Users League (AIVL) and AIVL's membership as well as face-to-face meetings with key stakeholders in Tasmania including Alcohol and Drug Services, Advocacy Tasmania, the Tasmanian Council on AIDS, Hepatitis & Related Diseases (TasCAHRD), the Alcohol, Tobacco and Other Drugs Council (ATODC) and others.

All interviews were either recorded and transcribed or verbatim notes were taken. Quotes from the interviews have been used throughout the report to illustrate the text.

1.6 Limitations of the Research

This is a fast growing area and a complex and evolving field. This means that it was not possible in the time available to undertake a systematic mapping of initiatives and activities and the description of models in the UK here is not exhaustive. However the researcher was able to draw upon other pieces of research providing overviews of user involvement initiatives and issues. This has made it possible to ensure that the major models currently in use have been identified and described. The approach taken was to identify those generally considered to be models of good practice and to look at them in some detail. However as much of this work has occurred in the past five years, and particularly in the last two to three years, there is no thorough exploration of the sustainability of models or any longer-term evaluation of their impact on the quality of services and/or on outcomes for those involved.

Care must be taken in using UK experiences to inform developments in Australia and in Tasmania particularly when mainstream service provision and the overall policy context is different. There is also the fact that in Australia human services delivery is usually seen as the province of state and territory governments which makes it more problematic than many other countries to develop national systems. Nevertheless developments in the UK can offer valuable clues about what might or might not work in Australia and what is required to promote consumer participation activity.

This report does not cover the involvement of families and carers of those with problematic

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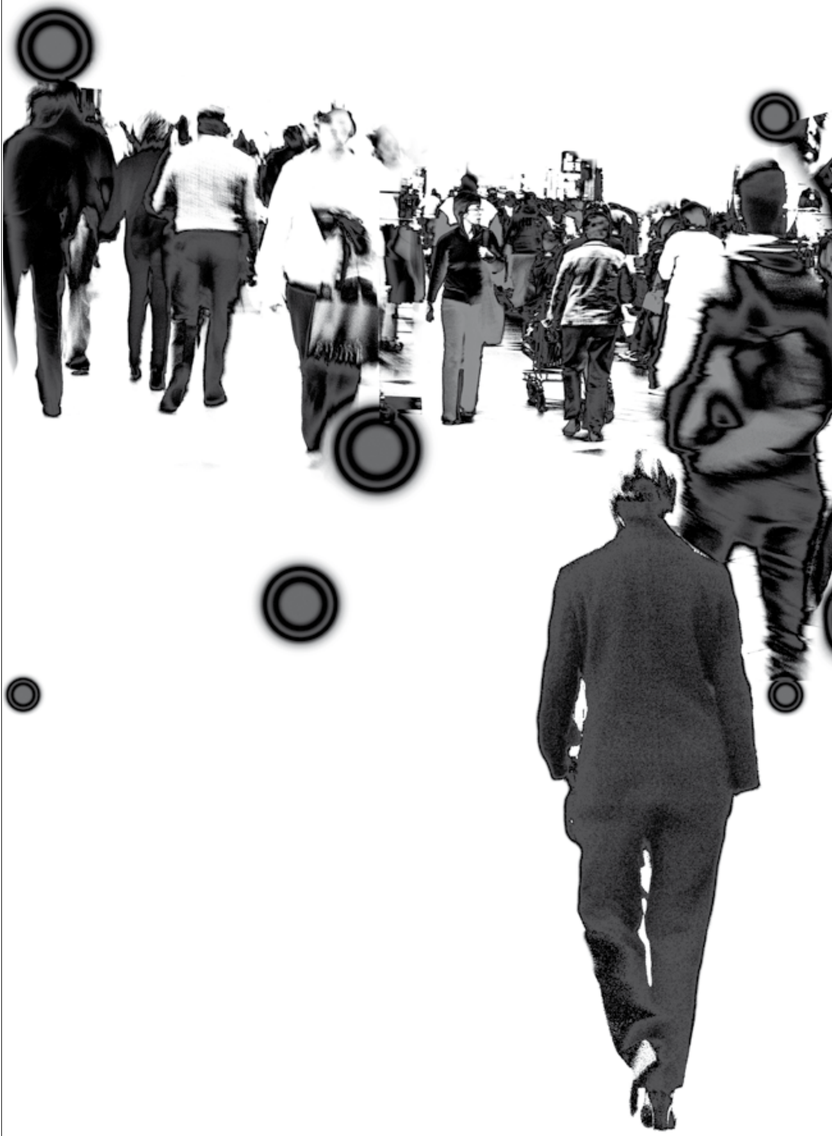
[3] Commissioning is the process of specifying, securing and monitoring services to meet needs.

substance use in the planning and development of services. This has lagged behind that of service users and meant that their needs have often been overlooked in service provision. However in the UK this is changing. Guidance (NTA 2008) is currently being developed for those who commission services about involving and supporting them and there is now a requirement for all workers to ask adult service users about their families and dependents. There is also a concern that families and carers should be involved separately to service users as they have distinct needs which can be in conflict with the needs of users.

There is a bias in this report towards the views and perspectives of those 'on the inside' – that is those who have developed a public profile as user involvement activists and supporters. This should be taken into account when reflecting on the findings of the research.



2. The UK Experience and Beyond

This chapter describes what service user involvement in the drug and alcohol treatment sector looks like across the UK, how it has developed, the policy framework and the key factors, themes and issues which have shaped the discourse.

User involvement activities in drug treatment services have been funded and promoted to a much greater degree than in the alcohol sector. This means that developments in the drug sector have proliferated and taken the lead in terms of good practice models. They are therefore the main focus of this report.

2.1 The Drug Treatment System

Treatment for illicit drugs in England is overseen by a special health authority, the National Treatment Agency for Substance Use (NTA), which manages the commissioning and delivery of drug treatment services. It was established in 2001 in response to growing concerns about the quality and efficacy of the treatment system. It aimed to address the inequities of provision and bring a wider strategic and clinical coherence to treatment in primary and secondary care. Alongside the setting up of the NTA in England, parallel structures were established in the Scottish Executive and the Welsh and Northern Ireland Assemblies. Each region in the UK now has its own drugs strategy and a patient involvement agenda supported by legislation.

Drug treatment services in England are provided through a mix of National Health Service (NHS) and community sector organisations commissioned by 149 local partnerships or Drug Action Teams (DATs) who are responsible for developing and delivering drug strategies to meet local needs. The Drug Action Teams represent local government, the primary care trust[4] (PCT), health, social and law enforcement agencies, local drug treatment providers, service users and carers. They work with the community to identify key issues and strategies to tackle drug supply, crime and disorder, to provide interventions in schools and to produce an annual treatment plan. Drug Action Teams liaise with joint commissioning groups[5] who are responsible for the allocation of resources to implement the annual treatment plan and consist of representatives from the NHS, local government care services, the police and probation services and increasingly service users and carers. The NTA assesses treatment plans, monitors national standards and allocates funds from a pooled treatment budget. Half of the funding for drug treatment comes from the Department of Health, a quarter comes through the criminal justice system and the remainder through primary care trusts and local authorities.

The treatment system in England is driven by the second National Drug Strategy (HM Government 2008) which covers four main areas: protecting communities, preventing harm to children, youth and families, delivering new approaches to treatment and promoting public information campaigns and engagement. The underpinning themes of the Strategy are about taking decisions locally, the critical role of treatment, drug education and supply side interventions and a focus on recovery and personalisation to ensure that the service user is in control (McGrail & Mackintosh 2008). There is also a focus on mainstreaming so that all services take account of drug users and a recognition that tackling a serious drug problem is as much about accessing housing or employment as about drug services. The Strategy had a dedicated budget of £398 million (or approximately $AUD 655 million) in 2008-09.

Since its inception the NTA has managed a huge expansion in treatment services and there has been record investment to increase the numbers in treatment and to move them through more rapidly. A report published when the NTA was first established (Audit Commission 2002) documented how many people struggled to get help and faced limited treatment options, lengthy delays, under-developed care management, poor service planning and poor collaboration between providers and other stakeholders. Two years later the Audit Commission[6] (Audit Commission 2004) documented a reduction in waiting times and more people in treatment. By 2007 the

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[4] Primary Care Trusts are freestanding statutory bodies within the NHS. They have responsibility for the health care needs of their local community and aim to improve health and address health inequalities. They receive budgets from the Department of Health and commission and provide primary health care and community services and commission hospital services for patients.

[5] Joint Commissioning Groups take delegated responsibility from DATs and involve all relevant agencies in commissioning drug treatment on behalf of DATs. DATs performance manage this work.

[6] The Audit Commission is an independent watchdog regulating the control of public finances by local authorities and the NHS in England.

numbers of people in treatment had doubled from the 1998 baseline and the Home Office estimated that the national average waiting time for treatment had fallen from nine weeks to one week (NTA 2009).

With better access to an expanded treatment sector there is now a move from the focus on reducing waiting times and increasing retention to establishing an evidence base for clinical interventions, re-discovering the role and potential impact of psychosocial interventions and keyworking (Wardle 2009). There is also an emphasis on promoting recovery and reintegration.

2.2 Policy Framework: The Development of Service User Involvement in Drug Treatment

Over the past ten years the role and impact of service users in drug policy and practice has become prominent and a number of writers have documented this growth and the national push to incorporate meaningful user involvement into every aspect of drug and alcohol treatment. Many of these developments have been led by injecting drug users and drug user groups. Involvement activities in the alcohol field have lagged behind and taken second place.

The origins of service user involvement in the drug field can be traced back to the 1970s with the development of new social movements critical of existing service provision – for instance in the mental health, women's, gay and black people's movements – and there was a push to make services more accountable to those who used them and less dominated by professionals (Cowden & Singh 2007). However political support for user involvement in the drug field has been attributed to the necessity to engage service users in addressing the public health crisis of HIV/AIDS and blood borne viruses like hepatitis in the late 1980s (Zibbell 2004). This instigated a move away from moralistic portrayals of drug use and the goal of abstinence to argue that services should work with drug users, including those who did not want to stop using, to promote practical methods to reduce drug related harm. This marked the birth of the harm reduction movement and involved recruiting injecting users into treatment and educating them to reduce the risks with safer injecting techniques and overdose prevention. It saw the establishment of the first needle exchanges, changes in prescription policy to make services more attractive to users (Efthimiou-Mordaunt 2004) and marked a transition from 'drug user' to 'consumer' and 'expert patient' capable of responsible choice and of value to policy makers and professionals. This laid the foundations for the contemporary situation where users are demanding a participatory role in service provision and policy making.

The 1990s saw the emergence of a strong user voice and an underground movement with no mainstream government support or financial backing and entrenched in a culture of political activism (Ford 2008). It included the launch of Black Poppy[7], the establishment of Mainliners, a self-help and advocacy organisation focusing on hepatitis C and HIV issues, the UK Harm Reduction Alliance[8] and the Methadone Alliance, a coalition of users and professionals aiming to improve the quality and availability of treatment (see page 71).

As late as 1997 there was no standardised quality of treatment and the treatment system was often based on the prejudices and whims of individuals rather than on evidence. There were long waiting times, sub-optimal dosing for those receiving pharmacotherapy and an acknowledgement from the General Medical Council that doctors were withholding treatment on the basis of moral judgments (McDermott 2006). In 1998 the new Labour Government launched its ten-year strategy for tackling drug misuse (UKADCU 1998). This set a target of increasing participation in treatment by 100% by 2008 and supported the appointment of a 'drug czar' to oversee the implementation of the strategy. In 1999 guidelines on clinical management were published and established that 'drug misusers have the same entitlement as other patients to services provided by the NHS and doctors must provide services whether or not the patient is ready to withdraw from drugs' (DoH 1999).

Two key policy initiatives during the last decade have promoted user involvement in drug

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[7] Black Poppy is a drug users' health and lifestyle website established in 2000. It produces a quarterly magazine.

[8] The UK Harm Reduction Alliance is a coalition of users, workers and educationalists aiming to put public health and human rights at the centre of drug treatment.

treatment:

- Section 11 of the *Health and Social Care Act 2001* placed a duty on all NHS organisations, including drug treatment services, to make arrangements to involve and consult patients and the public in planning, developing and considering proposals for changes in the way services are provided and decisions that affect how services operate (DoH 2001). This duty also applies to non-NHS service providers who provide services through contracts and service level agreements. It means that at national, regional commissioning and service provider level users and carers must be actively involved in the planning, delivery and evaluation of service provision to increase patient centred care. Drug Action Teams and Primary Care Trusts are annually assessed against participation standards set by the health and social care regulator for England.

- The establishment of the NTA to oversee and improve drug treatment. In 2002 it published Models of Care (NTA 2002) which set out a national framework to achieve equity, parity and consistency in commissioning and provision. The framework acknowledged the central role of users and carers by outlining their right to be actively involved in interventions, their own care and decision making. It laid out how users should be consulted about their own treatment and their basic rights that included receiving a care plan and standardised waiting times for treatment. In 2005 the NTA launched a Treatment Effectiveness Strategy (NTA 2005a) that placed an operational expectation on all providers to engage clients on an equal footing and ensure that their needs were respected. The NTA have issued a policy and guidance for Drug Action Teams on involving users and carers and requires them to report annually against involvement activities (see page 48).

In addition the 2007 guidelines for clinical governance (DoH 2007) emphasised that users should be involved in every aspect of their treatment.

2.3 Policy Framework: Service User Involvement in Alcohol Services

Current UK drugs policy does not class alcohol as a drug. The NTA's brief on alcohol is confined to the under-18s and alcohol treatment services are commissioned and funded separately from drug treatment services by Primary Care Trusts. Some treatment services deal specifically with alcohol, others with drugs and some are a mix. Those that are mostly alcohol do not come under the banner of the NTA which is the only central pool of money for local addiction services. This means that alcohol services either do some drug work to acquire some of the funding or lobby their Primary Care Trust or local government to do alcohol work. In some areas the Drug Action Team has become the Drug and Alcohol Action Team with responsibility for alcohol strategy but most commonly alcohol funding at a local level competes with budgets for tobacco, mental health, cancer and other health sectors. Despite evidence of increasing harm associated with the consumption of alcohol, expenditure on alcohol treatment accounts for only 6% of the overall drugs budget (Addiction Today 2010).

The issues facing those with drug problems and those with alcohol problems are different because of prohibition. Alcohol is a legal product which is widely available and means, as one activist pointed out, 'a totally different recovery journey'. Both providers and service users commented that it can be important to people who access alcohol services that they do not have to mix with people who use drugs.

> *There always was a huge divide and the street drinkers would call the drug users dirty junkies and the drug users would call them piss heads. (Service user group)*

However, for many people with drug issues, alcohol problems can become significant during the course of drug treatment and service users can fit into both categories. The funding arrangements have led to complaints about a lack of alcohol treatment and service users having to play down their use of alcohol and play up their use of drugs in order to get a service.

Alcohol services are also bound by the 2001 Health and Social Care Act and through Primary Care Trust and Drug and Alcohol Action Teams to involve service users. Some are pro-active in user involvement with structures to train and engage service users. There are also alcohol users involved in peer research initiatives, paid user involvement posts and one independent user-led organisation running peer services to support integration into the community (see page 65). However formal involvement in the alcohol treatment field has been rarer because of a lack of national policy or guidelines around involvement in the commissioning of alcohol services (Alcohol Concern 2007). User involvement has been dependent on local champions who have developed their own mechanisms independently. Interestingly, those with alcohol problems have been especially active in the drug user involvement movement where there is more likely to be an infrastructure for participation. They are also more willing to identify as a substance user and acquire leadership roles possibly because they do not have to contend with prohibition and the difficulties which can accompany identifying as a user of illicit drugs.

In order to encourage more service user involvement in commissioning Alcohol Concern – a national agency on alcohol misuse – produced a tool kit about user involvement for commissioners which outlined a model of involvement and gave standards and examples of good practice (Alcohol Concern 2007). There is now also a move to press for agencies which can work across all substances and which acknowledge the patterns of poly drug use. Scotland for instance has developed addiction teams which target both drugs and alcohol.

The Health Committee[9] has recently published a report on alcohol recommending that treatment for alcohol dependency should reflect the national model for drug treatment and that access to community-based alcohol treatment should be improved to match the availability of drug treatment (Health Committee 2009).

2.4 Policy Framework: the Regions and Internationally

The NTA does not oversee developments in drug treatment services outside England. This means that Scotland, Northern Ireland and Wales have forged their own path in terms of user involvement activities.

2.4.1 Scotland

In Scotland a number of developments are supporting service user involvement. These include:

- a recovery focused agenda which promotes recovery as the core aim of drug services (see page 28).
- the 2006 Quality Standards for Substance Misuse Services which emphasise the importance of user involvement and set standards for providers and commissioners to measure themselves against. However there has been no enforcement attached and no inspection process to ensure the standards are being implemented.
- a new inspection process that includes a scoring and grading system which has been introduced by the Care Commission, the health and social care inspection body. A service is only able to score the highest marks if it can provide evidence of service user involvement throughout its entire delivery of services. Scores are published and this means pressure upon services to improve their involvement activities.

Commentators describe a less militant drug user involvement movement than England with a weaker lobbying and campaigning voice. This has meant a slower growth of service user groups and more of a focus on improving services and providing evidence rather than wider issues like legalisation. However Scotland has rolled out a peer research model aimed at improving services (see page 51) and there are now developments to embed user involvement work in service provision (see page 52).

2.4.2 Wales

Since 2003 the Welsh Assembly Government has had a stated commitment to encouraging

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[9] The Health Committee is appointed by the House of Commons to examine the expenditure, administration and policy of the Department of Health and its associated bodies.

service user and carer involvement in the planning, design and delivery of substance misuse services under the 2001 Health and Social Care Act. However in the absence of a service user involvement policy developments have been ad hoc and dependent on local circumstances. Funding is now available from the Welsh Assembly and Substance Misuse Action Teams to prepare a service user and carer involvement strategy drawing on good practice in the mental health and wider health care fields from across the UK. There is also a push to ensure that any agencies bidding for service contracts are required to demonstrate active service user involvement along with meeting access standards and choice in treatment (Davies 2008). In 2009 the Welsh Assembly Government with the Wales Council for Voluntary Action held its first national service user conference. This has resulted in the establishment of four regional service user groups, a national service user network and an agreement to hold an annual service user led conference (UKFP 2009)

2.4.3 Northern Ireland

Northern Ireland has lagged behind the rest of Britain in terms of treatment choices and user involvement activity. Although services are bound by the same legislation as services elsewhere in the UK, implementation has not been monitored or enforced. There has been some progress but there is as yet no real commitment from statutory services or from substitute prescribing services to involve service users. The consensus is that it remains tokenistic and it has been particularly difficult to develop in the more rural areas. Informants described high levels of stigma where junkies are seen as 'the scum of the earth'. As one informant commented:

> *I distributed Black Poppy magazine and people realised there was a voice out there. They were unused to talking openly because they had been told they were crap all their lives. There was some funding for user involvement work but nobody was told why or how to access it or what it was for or any guidance about what to do with it. Historically we come from a society where if you put your head above the parapet as far as being a drug user you could have lost your knee caps. So in reality there is no service user input and no drive for it from the government. (Service user group)*

2.4.4 Republic of Ireland

Here task forces – or committees that bring together service providers, the Department of Education, the police, employment and training agencies and service users to oversee the provision of treatment services - have a responsibility to develop service user forums. Whilst this has not been prioritised in all areas and few resources have been made available locally to support the work, most task force areas now have a forum. Although there are a handful of well developed groups most lack stability and mainstream funding. Service users are represented on the National Advisory Committee on Drugs and there is now a push to develop a national network or voice to represent drug users. The new Irish National Drugs Strategy (DCRGA 2009) also includes alcohol. This has been welcomed and as one commentator said 'hopefully by having alcohol as part of the strategy it will make them look at all drugs a bit more rationally and at how they demonise drug users'. Out of 60 actions recommended in the strategy there is one reference to user involvement which refers to the development of drug user forums related to rehabilitation. Commentators however have expressed some caution:

> *I am happy that at least it's referenced in the strategy and that means there has to be some kind of commitment to the development of drug user forums. But the reference to the rehabilitation strategy I'm uneasy about because forums are not just about rehabilitation or making services work better. It is also about people who aren't going to rehabilitate, the most chaotic and causing the most harm to themselves. (Service user group)*

Certainly service users wanted to see the NTA having powers in Northern Ireland in order to promote a more unified and consistent service sector.

2.4.5 Other Countries

Across Europe a range of policy responses have been adopted towards drug and alcohol issues which have created differing environments for the development of user involvement activities. For example the Dutch have taken a pragmatic and liberal approach towards drug use and have strong traditions of involvement, Sweden has restrictive policies aiming for a drug free society and Germany has comprehensive public health, treatment and involvement policies. User involvement is beginning to emerge in Spain and Portugal (Degenhardt et al. 2009; Hunt et al. 2010). There are also examples of service user involvement influencing policy development in countries where the government has little sympathy for harm reduction principles. For example in Indonesia user networks are now contributing to national drug policy.

Increasingly there are a number of global networks which enable service users to share ideas and skills (Hunt et al. 2010). These include:

- an International Harm Reduction Association which runs an annual conference.
- an International Drug Users Network set up in 1992 to support injecting drug users to exchange ideas and develop user groups.
- the internet.
- an International Network of People Who Use Drugs founded in 2006. This is a first step in creating an international service user organisation and the organisation has been invited to give a formal address to the UN.
- the European Coalition for Just and Effective Drug Policies set up in 1994. This consists of 175 organisations and individuals affected by current drug policies working on drug issues.
- the International Coalition for Just and Effective Drug Policies founded in 1998 by 200 organisations.

Closer to home New Zealand has a comprehensive government policy framework to support consumer participation in mental health and in drug and alcohol treatment services with consumer advisers embedded in services. However commentators have raised issues about combining mental health and alcohol and other drug (AOD) consumer participation mechanisms whereby mental health consumer advisors also do drug and alcohol work rather than having specialists. This can mean drug and alcohol issues taking second place to mental health issues both in terms of the resources committed to developing consumer participation and in the composition of advisory groups and committees. The mental health consumer workforce is well established and it is only recently that the Mental Health Commission has taken an active role in advocating for the Alcohol and Other Drug sector (AIVL 2008).

Many drug activists in the UK would like to see much greater international collaboration between drug user movements in order to promote drug policy reform.

2.5 Other Policy Areas

Other policy areas in the UK impact on service user involvement in the alcohol and drug sector. The most significant are:

- **Putting People First** (HM Government 2007) which aims to transform the social care system and personalise services so they are centered on the individual and tailored to individual needs. This requires an extended dialogue and consultation with professionals, expanded choice and an enhanced user voice. There is a focus on self directed support where money is transferred to the service user to buy the services of their choice with the advice of professionals. Personal budgets to pay for treatment and other services in the alcohol and drug sector are currently being piloted in two areas. As long as there is some engagement with clinical treatment service users will be able to use the budget to buy services which can improve their condition: for example driving lessons, education and training or the removal of tattoos to improve employment prospects.

- a **welfare-to-work agenda** with an emphasis on encouraging pathways into work for drug users and promoting a closer integration between the treatment system and access to employment. A Treatment Allowance has been introduced as an alternative to Job Seekers Allowance and Employment Support Allowance. It allows those who cannot meet the conditions for Job Seeker benefits due to their treatment to have access to a replacement benefit and a safety net. There are no time limits and Treatment Allowance continues to be payable as long as the applicant fits the conditions for receipt. The NTA have been working with employment services to establish a drug coordinator in every district charged with finding employment opportunities for recovering drug users. Job Centre staff are being trained by ex-drug users in drug awareness so that they can provide a more responsive and flexible service. Income support claimants will be asked to undergo an assessment if they are identified as being dependent on or have 'a propensity to misuse drugs' and if this is considered to be a factor affecting their ability to obtain or remain in work. They will not have to accept any proposed treatment as a condition of receiving benefits.

- **The Independent Safeguarding Authority** (ISA), established in 2009, is introducing a new vetting and barring scheme to ensure that no one who poses a risk to children or vulnerable adults can work with them (Gilliver 2009a). The scheme is a coalition of previous schemes and broadens them to include a wider range of jobs and voluntary activities than before. People who can be barred include those with a history of acquisitive crime, fraud, addictive behaviour or persistent offending. Volunteering is a key area of service user involvement work and such histories are common among drug users who might be employed in peer support or voluntary work. There are currently serious concerns that the employment of current or former drug users in services as either volunteers or paid employees will be seriously impeded by the establishment of the scheme. As the alcohol and drug sector is the sector most likely to employ current and ex drug users there are also fears that this will decimate the workforce and have dramatic implications for voluntary work. Currently who gets involved can be determined by services and is based on the relationship they have built up with individuals which allows them to get a clear idea of the risk factors. Potentially the new regulations could have a major impact on their ability to assist people to move on. These concerns have been recognised by the ISA and they will be working with the NTA to resolve them.

2.6 The Current Situation: An Overview

Although service user involvement is now a statutory requirement and a priority area in all health and social care provision, there is no detailed national mapping of user involvement in the alcohol and drugs field making it difficult to present a national picture. The UK does have an established drug user involvement movement which has been described as 'a wide range of individuals, groups and organisations representing the interests of people who use a diverse spectrum of illegal drugs and operate in various contexts with diverse goals' (Hunt et al 2010). Within the movement there are two distinct groups:

- activists, who although concerned about poor treatment, also focus on the broader position of drug users in society and emphasise drug policy reform, fighting stigma and discrimination and building links with international activists. Activists are mainly drawn from those on opiate maintenance as well as from recreational users;
- advocates, concerned with practical improvements to local service delivery and harm reduction. This mainly involves drug users currently in treatment and those who are now abstinent.

Every service now has a service user engagement policy and locally many areas have active service user groups involved in commissioning; that is in the specifying, securing and monitoring of services to meet local needs. Drug Action Teams have appointed user involvement coordinators and routinely undertake consultations. A national survey of a representative sample of Drug Action Teams in England (Patterson et al. 2009) found that the majority (or 85%) involved service users in service development. However a lower proportion (48%) reported involvement directly with service commissioning processes. Thirty-eight per cent of Drug Action Teams reported that service user groups were in operation in their area and these had mostly been set up with the support and assistance of the Drug Action Team. There is a general acceptance of the value of user involvement and an acknowledgement that it is here to stay with the potential to enhance service delivery and development and to make a real difference (Patterson et al. 2008). However although participants reported changes in the organisation and delivery of drug treatment services as a result of service user involvement, there was little data recorded on outcomes of involvement. It is generally acknowledged that the NTA commitment to user involvement has been instrumental in these developments and in promoting them through regional and national events including a 'Voices for Choices' annual conference for service users (see page 72).

Yet there is also a consensus that overall across the country, and despite the rhetoric, the practical implementation of involvement at a local level has been patchy and sometimes tokenistic and the principle of user involvement is taking a long time to influence culture and practice in the drug and alcohol treatment field (Berridge 2008). There are still regional variations in the quality of and access to services and large numbers who do not benefit from treatment (McDermott 2009b). For many users the treatment journey is still a 'chaotic lottery' (DDN 2009) and at a national level there is an absence of a strong national voice or formally constituted drug user led organisation (see page 70).

2.7 Themes and Issues

A number of themes and issues have shaped policy discussions about how alcohol and drug treatment should be provided and about the developing role of service users in designing and delivering services.

2.7.1 The nature of addiction

There is a continuing debate about what addiction is and whether it is an illness, a disease or a character flaw, and research on addiction is constantly changing understandings. Previously it was thought that it was not possible to be addicted unless there were physical signs of withdrawal. Now addiction is seen more in terms of the extent to which an individual's life is taken over by procuring and taking drugs or alcohol. Research shows that the majority of the population are able to maintain a controlled use of substances which never becomes 'abuse'. However about 20% of those who take drugs go on to lose control over their consumption despite its negative impact on their lives, including criminality (Everitt 2009). This suggests that within any population there will be vulnerable individuals where taking substances leads to cognitive changes over which they have no control.

For some service users the disease model has been liberating and empowering. For others who see substance use and addiction as a reaction to and way of coping with past trauma, abuse and disadvantage it has been an obstacle to change. There are also wider tensions in society about attitudes towards substances where some consider they have a right to take the drugs of their choice while others make moral judgments about drug and alcohol usage. Comparisons are made with other social justice movements which have developed from treatment issues into human rights issues. For example in the gay rights movement when the condition of being gay was considered to be unacceptable the problems caused by the condition were numerous and unresolvable. Once the condition was accepted many of the problems disappeared.

This debate about the nature of addiction influences how people perceive the ability of service users to be actively involved and the nature of their capacities and incapacities.

2.7.2 Abstinence versus harm reduction

In the drug and alcohol treatment sector there has been an increasingly polarised debate between the value of abstinence based approaches where the goal is a drug free life and harm reduction and maintenance approaches where the goal is to reduce the harm caused by addiction while still respecting and acknowledging the value of abstinence. The harm reduction movement began in the early 1990s in the context of the HIV/AIDS epidemic and with investment in harm reduction approaches like needle exchanges. Less attention was paid to those approaches that focused on enabling people to become drug-free like residential and day programs and 12 step programs. The debate has come to prominence recently in discussions about substitute prescribing programs.

The National Institute for Clinical Excellence guidelines (NICE 2007) recommend substitute prescribing of substances like methadone and buprenorphine as the frontline treatment for heroin and opiate dependency[10]. Some people are put on high doses to prevent withdrawal and topping up with street drugs. Others are on reducing doses as a step towards recovery. The immediate aim is to prevent users resorting to crime to pay for illegal drugs and to stop dangerous injecting practices. Critics of this approach argue that too few of those receiving substitute medication complete treatment and emerge drug free. Rather once they are stabilised, and, because the system is geared towards crime reduction, there is little motivation to exit them from the treatment system. This means that relationships with drug workers can lack challenge, goals are not ambitious and this can promote low expectations about what is possible among service users.

> *A fundamental rethink is required about the purpose of drug treatment. Currently they invest in it because it saves money, prevents public nuisance and decreases the prison population. It's not about improving the disease or about social integration or about becoming a citizen again. The benefits of methadone are seen as a reduction in injecting, criminal activity, imprisonment and overdose and these are the markers to assess whether treatment is effective. Improved psychosocial functioning is not top of the list. All patients want to get off methadone and if you put patient centred care at the top of the list all the rest would follow. The question is do we expect enough from treatment and have we done a good job? Patients pick up on low expectations. (Academic)*

It has been argued that most users enter treatment after having tried unsuccessfully to give up themselves and with abstinence as a goal. If service user views were truly central in treatment, abstinence-based services would predominate rather than long-term stabilisation on methadone and harm reduction approaches which are the core of current practice (McKeganey 2004). Some would like to see a defined percentage of the treatment budget being directed towards abstinence approaches. Others argue that abstinence is an unrealistic goal for many people with serious drug problems, at least in the short term, and point to the substantial evidence base for the ongoing use of substitute drugs which currently forms the basis of national treatment policy.

> *Historically there has been a completely false divide in the way people talk about abstinence approaches and harm reduction. There are extremists at each end. People in the harm reduction movement would have no truck with the idea that abstinence is a valid objective and conversely others think that doing anything like giving out needles is cosying up to the devil. Most people realise you have a mixture of needs that people have at different points in their lives and all approaches have a legitimate contribution to make.*
> *(Writer and activist)*

> *For most of the people associated with our service user group there is the debate between harm reduction and abstinence-based treatment. You could speak to as many ex-users as you can in terms of how they got clean off street drugs and they will all have different experiences and all of those will either involve harm reduction or abstinence. Both of them hold as much weight in terms of success and to go down the route of total abstinence for everyone would be a nightmare. We are looking to develop abstinence-based peer support networks locally but it's about people having that choice. (Service user group)*

This debate can cause divisions in service user groups where the majority of participating users are stable and possibly drug free and may have disparaging and judgmental views of others who are still using or where advocacy positions might lean towards one approach rather than another.

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[10] Substitute prescribing does not apply to crack, cocaine, stimulants or cannabis. They require psycho-social interventions to change behaviour.

2.7.3 Prohibition and the War on Drugs

Current British drug policy, like drug policy in Australia, has been driven by prohibition and the criminal justice agenda which emphasises the social harm caused by illicit, as opposed to licit, drugs rather than the impact on individuals. This has two consequences. Firstly, it means that twice the resources are invested in treating crack and opiate addiction as on cannabis and stimulants and considerably more on drugs than on alcohol, despite the fact that alcohol remains a bigger problem in terms of the harm caused and its ability to destroy the lives of a percentage of its users. In order to access detoxification and other treatment services alcohol users may have to declare a drug problem. This means that people are tempted to lie about their drug use in order to get treatment which has a negative impact on tailoring the treatment system to meet individual need. Secondly, it means that, although there may be some impetus within the system to remove people from the risk of criminal activity by controlling their use and stabilising them on substitute medication, there is less impetus on recovery and enabling people to move off substitute medication. This is because the concern is about reducing crime and social harm rather than good outcomes for the individual.

Prohibition and the 'war on drugs' has recently received a lot of attention in the British media. The concept of a war on drugs was first used by US President Nixon in 1969 and since then drugs have grown in the public perception into a significant social menace, rivaling terrorism (Jenkins 2009). The underlying concept of a war on drugs is that demand can be curbed by eliminating supply. Increasingly however this approach is being rethought. Anti-prohibition campaigners see the global drug trade as a direct result of unregulated availability on the streets. Commentators have argued that making supply illegal oils the black market, drives trade underground and leaves consumers at the mercy of criminals while incarcerating large numbers of poor and disadvantaged people (Carroll et al. 2009). It has resulted in loss of life, misery and corruption, fuelled turf wars and enriched drug cartels.

Globally, international support for prohibition and drug policies heavily reliant on law enforcement is dwindling and support for harm reduction and drug law reform growing. There is an increasing desire to legalise the production, supply and consumption of all drugs in order to cut the link between drugs and crime, empty the prisons and ensure that supplies are pure and reliable as well as providing significant new sources of tax monies. Advocates of legalisation say that this would not deny the harm caused by drugs but would promote effective treatment and prevention.

Latin American economies are increasingly thinking about reforming drug policy. The Latin American Commission on Drugs and Democracy[11] is endorsing harm reduction and the decriminalisation of marijuana (Jenkins 2009). It is promoting a move away from the repression of users towards treatment and prevention so that users are no longer criminals but patients in a public health system with police targeting drug lords and organised crime. August 2009 saw criminal sanctions removed in Mexico for possessing any illicit drug in small quantities and Argentina is making similar changes for cannabis. Brazil, Columbia, Bolivia and Ecuador are considering partial decriminalisation. Spain and Italy have also already dropped criminal sanctions for the possession of small amounts of any illicit drug and the Netherlands and Germany have achieved the same effect by changing policing policy. In the US backing for decriminalisation is growing and California has pushed for a debate about legalisation.

In 2001 Portugal decriminalised the possession of all illicit drugs including heroin and cocaine for personal use (up to 10 days' supply). If apprehended, drug users do not get a criminal record but they may be referred by the police to a Commission for Dissuasion of Drug Addiction where regional panels might point them towards rehabilitation or community service programs. The legislation did not legalise drug use and there are criminal penalties for growers, dealers and traffickers. Studies which have been exploring the outcomes (Greenwald 2009; Hughes & Stevens 2007) have shown a rapid decrease in the use of hard drugs, especially heroin, among young people combined with a slight increase in cannabis use. There has been a large drop in heroin-related deaths, a 17%

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[11] The Latin American Commission on Drugs and Democracy aims to evaluate the effectiveness and impact of current drug policy in Latin America and contribute towards more efficient, safe and humane policies.

reduction in new drug related HIV and hepatitis notifications and a reduction in imprisonment of users and overcrowding. There has also been an increased uptake of treatment and overall it has meant a reduction in drug related public health problems. The resources used to prosecute and imprison drug users are now used to provide public health approaches including substitute prescriptions and treatment. This has required more than a doubling of treatment provision and there is now support for legalising supply as well.

Recently in Britain there was the widely publicised sacking of an academic from a government drugs advisory body who challenged the extent of harm caused by different kinds of illicit drugs compared to alcohol related harm. This encouraged a demand for a comprehensive review of Britain's drug policy, based on the realities of actual harm caused and including alcohol related harm. It also fuelled a concern among many stakeholders that repressive policies are rooted in prejudice and fear and not the realities of drug use.

The growing global movement that is challenging the war on drugs is leading a shift whereby drug prohibition as a cause of harm, rather than an instrument for reducing harm, is becoming more widely accepted. This pushes moves towards an alternative form of regulated drug supply and the possibility of putting the problematic use of legal and illegal drugs in the same framework where they are both seen as chronic relapsing conditions requiring treatment.

There is an on-going debate about the place of anti-prohibition work in the user involvement and harm reduction movements. Some commentators are concerned to distance themselves from anti-prohibition lobbying in order to assist the adoption of public health initiatives like substitute medication and needle exchange programs. But many others consider that prohibition actively contributes towards drug related harm by making every problem caused by drugs worse and burdening society with policing, imprisonment and healthcare costs. This means that ending prohibition becomes a legitimate campaigning activity for service users.

2.7.4 Recovery

The recovery movement represents a shift away from a treatment system driven by medicalisation, criminalisation and punitive systems to one based on individually tailored services and integration. It has been described as a fundamental re-design not a refinement of treatment and a transformation in the way we see addiction and its resolution. It has been described in the United States as a revolution and a 'remarkable social movement' which is just now beginning to take hold in the UK (White 2009). This has been accompanied by a debate about what recovery means and a growing national and international consensus supporting a consumer focused recovery approach as a basis for building services and support.

Recovery is a reaction to the failings of the current system where approaches lack a scientific evidence base, where there is no vision or hope of change and where people are discharged with little ongoing support. This fuels a high relapse rate where fewer than half of those in treatment complete it and only a minority receive continuing care. As White has pointed out there is no other condition where if individuals become symptomatic they are thrown out of treatment and told they have had their chance (White 2009).

A recovery model requires post treatment interventions based on partnership, networks of formal and informal services and volunteer programs where individuals can recover in their own environment. It can also spawn alternative peer-based support. It recognises that people's struggles are often due to stigma and discrimination and its crucial elements are about giving people hope, housing and employment opportunities and a long term process of personal change. Recovery is about working alongside service users rather than dealing with them as passive recipients of care (Wardle, 2009) and seeing them not as deficient and dysfunctional but as experts in defining their own needs, wants and preferences. The recovery movement has been strongly promoted by the expanding population of ex-service users who commonly work in the drug services industry and can act as role models by demonstrating that change is possible. It also follows the recovery movement in the mental health field where it has been a long established concept.

The UK Drug Policy Commission[12] recently convened a Recovery Consensus Group to outline a vision of recovery as a starting point for discussion among policy makers and other stakeholders (UKDPC 2008). It outlined the dimensions of recovery as the building of hope, aspirations and a meaningful life with participation in society, control over substance use and maximising health and wellbeing. It also identified that developing recovery-orientated services required a different relationship between providers and users and was associated with different types of support and interventions. The Commission's work has also challenged the increasingly polarised debate which has portrayed abstinence and maintenance approaches to treatment as an either/or debate and where some protagonists have suggested that substitute prescribing is incompatible with recovery (McKeganey 2004). Others argue that recovery is about making the best out of your life (McDermott 2009) and is personally defined.

> *Recovery is completely personal and what it is depends on the environment. In inner city areas it requires housing, work and training. It is a huge complex area where some things only work with some individuals. For those in care, in prison, sex workers, injectors, it's very different to a professional worker. Some people will not stop using substances, or cannot, and there must be a way for them to be helped. If you can get someone who has been absolutely chaotic and ruining their health onto a stable script and a reasonably stable life that is in fact part recovery. That's them doing the best they possibly can in this life. I am not against AA or NA but it's a lot to expect people to get completely clean and then go on. There have to be lots of avenues for people to try and lots and lots of failure points. It's okay to fail because that's the illness but much of our rehabilitation is too spiritually punitive. We are ashamed, we are guilty, we don't need to be constantly told that. We need to be treated with respect and dignity and gently and we'll get there. (Service user group)*

> *A lot of people think recovery is about abstention and it isn't. It's about getting people to a place in life where they want to be. People who access our service, the choice is theirs to drink or not and if they choose to drink we hope it will be at safe levels. For me, and many others, abstention is the only way but stopping drinking is not recovery, it's just one small part of it. (Service user group)*

The recovery movement currently lacks a strong evidence base which means it is treated warily by those commissioning services. In response to this a Recovery Academy was established in 2009 (Best & Bamber 2009) to systematically chart what is happening around recovery across the country and collate an evidence base recording success and innovation. A UK Recovery Federation is also being established to encourage the growth of recovery networks and to establish an accreditation body to support recovery orientated integrated systems. The majority of board members will have a personal experience of recovery.

A recovery focus is becoming a core part of drug and alcohol policy. The new National Drugs Strategy in England (HM Government 2008) has been described as radical in promoting a recovery agenda by offering a new focus on services to help drug users re-establish their lives and to use the opportunities created through welfare reform to establish incentives to move into treatment, employment and training (Wardle 2009). The recovery movement has also become a powerful force in Scotland where it is a core part of the drug strategy. The NTA is now focusing attention on long term recovery and resettlement particularly for that group of people whom critics claim have been 'parked' on methadone or other substitute treatments. It has recently published a guide on commissioning for recovery for local drug action teams (NTA 2010) with the aim of creating recovery-orientated drug treatment systems across England.

> *Recovery and the concepts around that introduce a whole load of really important ideas that are essential to improving the treatment system in a humane and user sensitive way. If people genuinely embrace those ideas you will begin to get a treatment system that can transform. There are important ideas about recovery as a process not an end place and that the benefits of*

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[12] The UK Drug Policy Commission is an independent charitably funded body which aims to stimulate debate around drug policy.

recovery should not be made inaccessible to those with chronic conditions. Some say it's been polarised between harm reductionists and abstainers but it's between narrow minded people and open minded people. (Researcher and activist)

3. Challenges of Implementing Service User Involvement

This chapter explores the challenges involved in developing and implementing service user involvement activities in alcohol and drug services in the UK. It combines research and policy literature about the difficulties and the successes with the experiences and views of informants who participated in the research. It identifies a range of hurdles which interconnect and overlap in complex ways and goes on to outline the range of models that have been used to progress user involvement activities.

This chapter draws heavily on the work of Fischer and Patterson. Fischer used case studies of four drug services – two specialist prescribing services and two residential rehabilitation services – to take a detailed and critical look at the difficulties in establishing user involvement activities in drug treatment services (Fischer et al. 2008). Patterson undertook a national survey which assessed the extent and nature of user involvement in a representative sample of English Drug Action Teams and a qualitative study of stakeholder perspectives on user involvement in six Drug Action Team areas (Patterson et al. 2007, 2008).

What they both found was a complex entanglement of influences and tensions, competing management priorities and funding difficulties. They identified two significant obstacles: an absence of clear objectives and a disjunction between service user involvement and other policy goals related to the drive to address drug related crime that underpins policy. There are also particular difficulties in challenging the stereotypes held by many providers and how these have influenced service provision. Although many of these factors also apply to other health sectors, particular to drug treatment is the impact of stigma and discriminatory behaviour, the social status of drug users, their social exclusion and the mistrust of authority that many service users have. These factors all profoundly impact on service user involvement and inhibit it (Patterson et al. 2008).

3.1 The Perceived Characteristics of Service Users and the Attitudes of Professionals

It is often argued that user involvement is dependent on having champions or professionals within the mainstream who proactively encourage it. One of the biggest barriers is therefore identified as professional attitudes (Bryant 2001).

Many service workers have deeply held stereotypes about users that lead to discriminatory practices in provision (Zibbell 2004) and the fear, ignorance and moral judgements about illicit use and lifestyle choices mean that users become exempt from the basic rights afforded to other NHS patients (Ford 2008). As one commentator stated, these negative and moralistic views have become embedded in the fabric of treatment services and mean that addiction services are not based on the interests of patients but on the assumption that every user lies (McDermott 2002). This leads to practices which infantalise, humiliate and extend dependency rather than empower and liberate, and this does not provide a good basis for user involvement. For example urine tests and supervised consumption may be necessary for chaotic users seeking stability but because so many workers believe that no one voluntarily seeks treatment they are imposed as a condition of treatment for all. With the exception of some mental health treatment there are no other health areas where patient compliance is enforced through coercive procedures.

Some chaotic and dependent substance users can breach treatment protocols and misuse facilities (Neale 1998). Fischer found that some providers as well as some users saw service users as manipulative and untrustworthy. This was underpinned by beliefs that clients denied their addiction, were resistant to treatment, were dishonest or had complex behavioural problems. Providers believed that chaotic lifestyles, vulnerability and an inability to retain information made users incapable of making informed choices. This meant that involvement activities were not seen as feasible or appropriate because it was assumed service users would exploit them, for example by deferring detox or requesting more medication. More commonly providers argued that users had unrealistic expectations about waiting times, the amount of support available and the ease of becoming abstinent and as a result involvement should be limited so that clients did not rush into treatment with unrealistic ambitions that increased the likelihood of failure. These perceived characteristics can overshadow attempts to establish user involvement activities and as one active service user said:

> *To be a credible person – if you are late to a meeting it's assumed it's related to your drug use, not that your child is in hospital. There are double standards operating. If I miss an appointment at school or I'm out when the health visitor calls it's immediately seen as related to drug use. No parent could stand up to that kind of scrutiny. You are meant to be grateful for user involvement but it's all about them letting us do it. There is no respect for the knowledge and you are not seen as an expert. (Service user representative)*

Patterson found that the negative assumptions of professionals could have a disempowering impact where service users were blamed for their addiction, seen as undeserving, suffering from self-inflicted problems, treated with contempt and had their problems disregarded (Patterson et al. 2008). This undermined their self worth and confidence and became a barrier to seeking treatment generally. The relationship between users and providers is often one of mutual antagonism which can undermine the therapeutic relationship (McDermott 2002). Users may see the main role of the service as providing a route out of criminal activity through a supply of legal drugs on a maintenance prescription. Workers try to control access to legal drugs by ensuring users get some but not too much and this can accentuate the power differential and cast workers as agents on social control.

> *Frontline staff have an 'us and them' approach. They may be excellent at their job but protective of clients and feel they aren't informed enough to have views. When people first become drug free they are often emotionally immature and lack social and people skills so staff feel they have to stay in charge. There is a lot of resistance to user involvement especially among workers who see the histories of abuse and trauma and disadvantage, illiteracy and see people diverted into user involvement as anti-recovery. They also feel spied on and criticised rather than it being about making services better. Long term staff find it most difficult. (NTA manager)*

Patterson, in a national survey of user involvement activities, identified that although professional hostility to user involvement was not widespread there were five distinct organisational approaches:

- the protagonists who express a philosophical and practical commitment to collaboration with users;
- the pragmatists where user involvement is obligation based and outcome orientated;
- the skeptics who are ambivalent and only seek users' input in limited areas;
- the abstainers who see users as incapacitated and exclude them beyond their individual care; and
- the avoiders with an apparent lack of knowledge about the user involvement agenda and an avoidance of the debate.

She also found ambivalence among providers due to a perception that user involvement is a complicated management process and/or that providers are treatment experts and best placed to make decisions. This is a view shared by many service users. As one informant said, workers, particularly in the NHS, may themselves describe a sense of powerlessness and minimal influence on service development. This means that they are unlikely to encourage users in what is seen as a futile quest.

If staff attitudes are considered to be one of the key attributes required for effective user involvement there are questions about whether it is more efficient to teach attitudes or knowledge. Should the goal be a highly trained workforce or one with a better attitude (Wylie 2009)?

3.2 Service User Perspectives

Patterson, describing a wide variation in levels of involvement, commented on the limited number of users seeking to participate formally in existing user involvement structures (Patterson et al. 2008). People want to participate in order to contribute, to give back and through a desire for social justice. There are also incentives such as training and skills development as well as short term incentives like cash, food and the alleviation of boredom. Many also see user involvement as a therapeutic extension of treatment or aftercare and a bridge to normal living. However these motivations are also challenged by illegality, stigma and prejudice which make it problematic to publically disclose drug use. They are also challenged by a distrust of services due to previous experiences of punitive, authoritarian and coercive treatment. Service users can be confused about what involvement is and how people become involved and focus on the relationship with their key worker rather than the service as a whole. Some may have problems with literacy. They can be cynical about the value of their input or feel the only feedback mechanism available to them is to drop out.

Low self-esteem is common amongst service users who may consider themselves to be 'the dregs of society'. Without a degree of empowerment it is unlikely that they will have the capacity to become involved and without their involvement they are unlikely to feel empowered (MP Consultancy 2008). So a key challenge becomes engaging with individuals who may have a very limited concept of what involvement means and who have to progress from being angry about what does not work to negotiating and communicating (Simpson & House 2003). This can require bonding to a group to build personal confidence before users are able to negotiate with providers. But apathy, cynicism and misplaced anger among users can operate as big barriers for establishing sustainable service user groups. Clients may want quick solutions because of their desperation for assistance and this can militate against user involvement because of their reluctance to question professional judgments or ask for particular treatments in case it slows down the treatment process (Fischer & Neale 2008). Some feel that more responsibility would be stressful and a burden, especially at the start of treatment when they are struggling to cope. Others argue that the opposite of user involvement would be most likely to help them reduce their drug use. What they needed was staff to exercise pressure and make demands on them - 'a kick up the backside'.

At a broader level there have been divisions within the drug user movement which have militated against a strong, coordinated national user voice in the UK, diverting energies away from local implementation and alienating current service users. Commentators see the movement split between 'drug user activists' and 'service user involvement activists'. For the drug user activists anti-prohibition and treatment are inextricably linked and the development of user sensitive services is dependent on decriminalisation and a reform of national prescribing policy. They argue that unless the user movement challenges prohibition it is just a service lobby (Mold & Berridge 2008), that user involvement is about humanising an inhumane system and that the radical agenda of the user movement has been subverted into discussions of the minutiae of current provision (Bryant 2001). Some also argue that state sanctioned, controlled and supported user involvement has effectively neutered a potent and powerful political force and that 'it's been assimilated and institutionalised and entered a dark age of apathy' (Garratt 2007). The more government has tried to empower users through user involvement the more they have distanced them due to inherent power imbalances where they can only be involved in certain policy-defined ways and not on their own terms (Patterson et al. 2007). As one informant said: 'we have been offered every element of participation but we have not been offered power'.

> *There is a human rights agenda which doesn't fit with the business model of the NTA which is about using service users in the design of services and getting feedback. The current generation of users wish to be involved but are committed to the medical model of drug use and to treatment issues. They are not interested in broader and bigger issues about human rights which are seen as irrelevant.*

> *This is an obstacle to development. There is a whole swathe of people who think of themselves as user activists and where treatment is only one concern, along with prohibition and the right to use drugs of their choice. (Writer and activist)*

At the other end of the spectrum, service user involvement activists may consider that the more radical end has ignored the realities of many drug users' lives and that the domination of the national user involvement agenda by a small number of high profile users has undermined the credibility of local user involvement activities.

> *Drug activists are very different to service user involvement activists and don't represent the disadvantaged on housing estates who are living in shit. Legalisation has become a huge distraction and having no home or work is a bigger issue. For example drug consumption rooms are an interesting concept which has become a cause celeb for the legalisation lobby but are not what is needed in public health and should not be a priority for public money. We need a spectrum of approaches but when resources are given to drug activists and not user involvement it's an inappropriate use of public money. (Activist)*

> *The politics of the user movement are very competitive and the loudest voices don't necessarily reflect the interests of others. There are constant fights and dominant personalities. The temptation is to look for user champions or people with a professional view but they tend not to be radical or willing to challenge the system. They are tokenistic or tame users. The two worlds need to merge and the systems need to connect. (NTA manager)*

Diversity within the drug user movement is reflected at an individual level where the differing needs and wants of, for example, opiate users, those involved in criminal activities and different age groups, genders and ethnic groups present a challenge to providers in supporting user involvement activity. As one commentator said, user involvement is predominantly very white and very male. There are also non-service users who are not using services because they are unhappy with them and issues about how best to involve them. Those responding to suggestion boxes and surveys are usually self selected and may be unrepresentative of others. One approach is to use independent interviewers who can provide useful insights into the needs and views of non-service users and those who do not otherwise engage (Christo 2004).

3.3 Strategic and Structural Difficulties

Although a commitment to user involvement might be articulated in policy, its credibility can be undermined by a number of structural and strategic factors. These include a lack of resourcing, a failure to embed involvement into strategic objectives and service provision, an absence of guidance or mechanisms to promote enforcement and differing goals among key stakeholders. There are also the practical challenges of developing user involvement in rural areas with poor transport and dispersed services.

User involvement is not free and commonly requires dedicated resources and ring fenced funding. One area where resourcing can fall short is in reimbursement to service users for contributing their time and expertise and for travel and subsistence expenses. Although the NTA has produced an expenses policy and Drug Action Teams and services are required to have user involvement and remuneration policies, payments do not always happen or they leave people out of pocket. Some users have ceased to volunteer because they cannot get their expenses paid. There are also real barriers to reimbursements like a requirement that any money should be paid into bank accounts[13] or that identification is required. Payments can also impact on benefits. One informant described attempts to use vouchers rather than money as 'very insulting demonstrating that users can't be trusted to cope with cash because it's assumed they will buy drugs. It's infantalising'.

> *The rewards for being a service user representative are very small. It is NTA policy but each borough has its own version. This borough pay a maximum of £20 per week*

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[13] In the UK one in 12 households or 2.8 million adults did not have any kind of bank account in 2006 (CAB). In 2010 1.75 m people had no access to a current or basic account. Source: HM Treasury.

> *whatever you do and you can get an email on Wednesday asking for a written response to a report by Friday. They don't pay for your internet connection or printing. You wouldn't treat your own workers like that. (Service user representative)*

> *Most people think user involvement is something they shouldn't have to pay for or something they would pay a lot less for than they would do for any other service. That's a struggle because no one funds a user involvement post and no one funds for the building or equipment or rent or anything like that. We just get funded for a certain amount of days that they use our time. One of our biggest problems has always been finances. (Service user group)*

Some see a key factor as the failure of the NTA to produce guidance about how to do user involvement or any baseline standards. In the absence of specific guidance about implementation, health services have employed diverse mechanisms, often unsystematically, to engage users. This has meant that organisation led mechanisms predominate, bottom up involvement is limited and there is a wide variation in the level and quality of user involvement across the country. Neither has implementation been monitored systematically.

Why didn't the NTA provide baseline standards for user involvement as they did with other things? There was great enthusiasm but also a message that we won't force you to do it because it's too much work. So they stopped at issuing any guidance about how to do it and there is no tool kit. There are great ideas but no detail and development and implementation is always in the detail. There are pockets of very good practice at local level and that's where the strength is in user involvement, at the grass roots. But although local areas are asked to do it they are never pulled up for not doing it or for doing a token approach. And even good practice in local areas doesn't connect to strategy and planning. (Activist)

There can be a lack of clarity about what service user involvement is and providers and service users do not always agree on its meaning and purpose. It can also be insufficiently goal orientated and over ambitious in its aims (Ford 2008). Health services can find it hard to distinguish between consultation and information provision which means that user involvement may be attempted at a late stage when major decisions have already been made and users are invited to rubber stamp them (Bryant 2001). Although service users may see involvement as a right and campaign for legal and attitudinal change, the NTA, Drug Action Teams and service providers see it as a responsibility with the goal of increasing the capacity of the treatment system and improving quality (Garratt 2007). Staff may be confused about what is being asked of them and may feel threatened by what can be a change in the culture of working.

> *The NTA say you have to do it but there is no shared understanding about what it is, is it involvement, representation, participation? DATs [Drug Action Teams] have to do it but understand it differently to users and providers. Genuine user involvement is where it is dedicated to pro-active involvement in issues which concern users and in providing a service, not just policy. It does work in some isolated areas but it also falters as they are meant to do it but don't know how. Every DAT [Drug Acton Team] will say it has some user representation but the question is the quality of it. (National service user-led organisation)*

There may also be an unclear responsibility for implementing user involvement especially when there are complex and coterminous organisational structures and a lack of strategic user involvement planning at Drug Action Team and service levels.

Patterson described how, although managers and workers saw legislative obligation as the primary driver for user involvement, they also stressed that the pressure to achieve targets detracted energy and resources away from user involvement. The requirement from government to demonstrate user involvement can mean that it becomes a formal, tokenistic procedure using a tick box approach (MP Consultancy 2008). A key factor here can be a failure to link user involvement to other specific strategic objectives so it is seen as extra work rather than a core component of all service delivery activity. Staff may have to weigh clients' wishes and their desire to meet them against the need to meet official targets, abide by national policy or uphold a professional duty of care. This may be compounded by their inability to promote choice in treatment because of limited capacity. A failure to react to user views and virtually non-existent opportunities to influence services can lead to high levels of frustration as users realise they are unable to effect service improvements (Fischer et al. 2008).

> *Many services struggle to deliver care and don't see user involvement as core business but rather as problematic and what is the point if they only have three years and are at risk of not getting re-tendered. (Activist)*

This suggests that those responsible for commissioning services and who establish positions responsible for service user involvement might also wish to give that position responsibility for embedding involvement in service delivery as well as at the commissioning level. Unless this occurs development at the service delivery level is slowed as services are given a ready made group of service users to call on for involvement rather than developing their own.

The characteristics of some services may act as an impediment to developing user involvement. For example residential rehabilitation programs often maintain a structured therapeutic program that includes mandatory elements that are directive and authoritarian and where the service user is not encouraged to take decisions. There are also criminal justice interventions that are compulsory and although service users can still be engaged in the treatment process, there may be fewer opportunities for user involvement. Locally it is easier to develop involvement activities if there is a structured day program which can foster the development of relationships. In a homelessness project working with chaotic users this is more of a challenge.

Working in rural areas with dispersed populations can present particular challenges. This may require a bigger input of resourcing to facilitate contacts and networks. However in some areas networks will already be in place:

> *The user community here is a village of its own because anyone who has ever used will know someone else who has used and the more rural it is the more this applies. We hold groups in as many towns as possible and usually we hang onto the treatment system and borrow one of their buildings and open it up at night or the weekends. People turn up and we have a lot of fun. We now have five volunteers running across the country. So although geographically it's a nightmare, there is a lot of network out there and the relationships which have built up between those who provide and those who take the service is very close. (Service user group)*

Lastly of course user involvement work does not always have positive outcomes, particularly if it is done badly. It can create difficult relationships with staff, increase user dissatisfaction with services, promote user stress and frustration and slow decision making processes. It can also lead to the further exclusion of people who do not use services and those who drop out of treatment.

1. Lessons for Australia - making it happen

- A commitment to user involvement must be underpinned by proper resourcing, particularly for volunteer reimbursements.
- A commitment to user involvement must be part of the performance standards for the organisation's funding.
- The commitment must be embedded into the strategic objectives of an organisation.
- The commitment must also be embedded into service provision so that it is a core part of service delivery activity.
- Stakeholders need to agree on the goal of user involvement, its meaning and its purpose.

3.4 Establishing an Evidence Base

Although all providers of state funded health and social care services in the UK have had a statutory requirement to involve service users since 2001, formal evaluations of the impact of this in the drug and alcohol field have rarely been conducted and there has been a lack of academic studies. This has meant a limited evidence base about the outcomes and effectiveness of user involvement activities (MP Consultancy 2008). At an individual service level there is a growing body of research evidence, best practice examples and initiatives that have been seen as successful, with positive outcomes, but many are unstructured and not monitored, recorded or evaluated. Documentation can be a low priority for activists, many key figures have died prematurely and preserving history has been the exception rather than the rule. This means that the knowledge gained from experience is not shared. Commentators have attributed this to a number of factors, the most significant being prohibition and the entrenched stigma attached to illicit drug use (Hunt et al. 2010). Despite a growing number of 'out' users who contribute their experiences, participants can be reticent about declaring their user status because it means a risk of facing criminal sanctions, losing livelihoods and stigmatizing families. Their activities therefore remain invisible and go unrecognised. As Hunt has pointed out, this would cause outrage if it applied in other areas such as gender, ethnicity or sexuality.

Despite this lack of a comprehensive evidence base many benefits are claimed for service user involvement activities. For service users involvement in individual treatment and care plans and in broader service delivery and policy is seen as improving client retention rates, producing higher levels of satisfaction with services, reducing contact with the criminal justice system and promoting entry into education, training, employment and recovery (Bryant 2001). It builds confidence, self esteem and skills, challenges the dependency which is fostered by long term involvement with services and utilises the direct experience of what works and what does not to improve services. For providers it leads to a better understanding of what service users need, avoids service features which are unacceptable to users, promotes closer working relationships and is becoming a vital part of service development (Schulte et al. 2007). It can inform training and reflection on practice. For those responsible for commissioning services and planners claim it helps to ensure that provision meets the needs of local populations and identifies gaps in services.

Beyond the rhetoric however how far has the service user movement been able to change policy and influence and improve service quality? Patterson identified that although it can be difficult to isolate the effects of user involvement from other factors that influence organisational change, service users and providers describe a number of instances where user involvement had led to or hastened change in service delivery (Patterson et al. 2007) ranging from decisions about where new services should be located to changes in opening times. A number of service user groups who participated in this research were asked for examples of ways in which they had influenced services locally. They described:

- being on interview panels for Drug Action Team managers and commissioners;
- lobbying, resulting in the establishment of new services such as substitute prescribing, expansion of needle exchange programs into police stations, mobile services in rural areas, women-only housing, talking therapies and treatment in primary health services;
- challenging established practices - for example blind reductions (see page 38) or urine testing;
- becoming a commissioned service; and
- sitting at Drug Action Team Board level and influencing policy: for example, strategies on drug-related deaths, blood borne viruses, aftercare services and partnership working.

> *We saved one treatment completely. Diamorphine was going to disappear because the company that made it stopped making it. We have the biggest clump using it in Cornwall and no one was prepared to do anything about it. We used our networks and insisted on having a meeting with the Department of Health and lobbied like mad to have it back. That didn't work so I went to the Guardian and they ran a story about diamorphine and human rights. It's now*

> *a commissioned service and in the annual treatment plan. Also no one in Cornwall was able to go to a GP because they simply didn't want to treat us. That was one of our biggest moans, why can't we be treated as normal, why do we have to travel to Red Ruth which is 80 miles away and costs a bomb? We now have seven trained GPs and 20 local enhanced services trained by service users. (Service user group)*
>
> *One of our successes was that people on methadone treatment had their medication cut for behavioural issues, nothing to do with their drug use. Things like smoking in the building or loitering or turning up late. We managed to change that. (Service user group)*

Blind reductions were previously in common usage. This involves reducing scripts after failed urine tests but topping them up with water so that users are unaware of the reduction. When they complain that the script is not working for them and holding cravings at bay they are told it is their imagination. This was common practice but has no demonstrable clinical benefit or evidence base. This practice has now been greatly reduced after listening to the voices of service users.

User influence has also recognised the particular needs of parents and those in full time employment and how to better provide for them and integrate them into the treatment that is being offered (Ford 2008).

2. Lessons for Australia – does it work?

- Building evaluation measures into user involvement initiatives is essential.
- In the UK, research has indicated that for service users, service user involvement has:
  improved retention;
  produced higher levels of client satisfaction;
  reduced contact with the criminal justice system; and
  increased entry into education, training, employment and recovery.
- In the UK, research has indicated that for service providers, service user involvement has informed service development and efficacy.
- Changes which have come about due to service user involvement include:
  recruitment and accountability of employment practices;
  establishing new services;
  improved match between service user needs, demands and service responses;
  established practices challenged and abandoned; and
  influencing health policy.

3.5 Dimensions of User Involvement

Across the UK many service users are now involved in their own treatment and that of others through a range of mechanisms and with a number of different goals. It is not possible to identify a single best practice model as approaches are multi-faceted and it is also difficult to form a typology because in reality different models are blurred. Goals can range from responding to public health threats, improving treatment and quality of life, shaping and reforming policy and legislation, reducing stigma and increasing public understanding. These goals can be achieved through a variety of different methods.

At its most basic, involvement is about service users participating in their own treatment and passive engagement mechanisms such as suggestion boxes, comment books or satisfaction ratings with services. More active forms of consultation are managed by providers and give service users a degree of power. These include users as members of decision-making bodies, monitoring and inspection of services, participating in staff recruitment and education and training, volunteer work and establishing and providing services. There are also independently organised user groups that are self determined. In practice these may be nurtured by the treatment system as part of a process of involvement but become independent with their own agenda (see page 64). These service user groups can employ all or some of the many mechanisms of involvement described here. In addition there have been attempts to develop national service user-led organisations working to improve policy and planning at a national level.

Patterson, in an exploration of levels of user involvement in England (Patterson et al. 2007), found a number of different models and described a typology of methods and mechanisms with the most common being representative and advocacy models. They include:

- a unionised model with service based user groups contributing delegates to advisory groups at Drug Action Team level;
- a volunteer model where trained volunteers work as team members at service level promoting engagement with users and facilitating communication between the Drug Action Team, services and users;
- an independent user group led model with the group having representation at Drug Action Team level and regular meetings with service managers. The group may also be involved in educating other users about their rights, their treatment and services, campaigning for better local services, conducting training for other agencies and setting up peer support groups to provide alternative support services; and
- an advocacy model centered on a user involvement worker employed by the Drug Action Team, participating in Drug Action Team committees and intervening at service level on behalf of users.

The advantages and disadvantages of various models can be assessed on the following criteria (Alcohol Concern 2007):

- how close service users are to the decision making process;
- how far the model is user led and how independent service users are from those responsible for commissioning services or other services;
- what changes involvement has made;
- how the model connects with the population of individual service users including minority groups;
- whether there is a diversity of methods of involvement from which service users can choose;
- what training and support participating service users receive; and
- what processes are in place to ensure that the model will continue and is sustainable.

Patterson found similar methods being used in both the NHS and in community sector services. However they differed in that in NHS services user involvement was viewed as motivated by obligation although there was a consensus that it had the potential to improve services. Community sector services on the other hand expressed a rights based commitment to having users at the heart of services.

All informants were clear that user involvement is not about complaints but about using the voice of service users to develop services and improve treatment. So although formal complaints mechanisms exist, or should exist, in all services, they are not seen as mechanisms for user involvement but as a last resort for the service user dissatisfied with the treatment they have received.

3.6 Approaches

Within any model a number of different approaches and mechanisms can be used which operate at varying levels.

3.6.1 Involvement in Individual Treatment

Involvement at the level of individual treatment is commonly seen as the first step in progressing user involvement activities.

Fischer explored the complexities of involving service users in their individual treatment by studying staff/client relationships and user involvement in decision-making in two community treatment agencies and two residential rehabilitation services (Fischer & Neale 2008). The research found that although implementing involvement in treatment decision-making had the potential to trigger higher levels of conflict, this tended to be latent rather than overt. Users wanted to cooperate with treatment and often adopted non-confrontational forms of covert resistance to decisions. Staff also used involvement mechanisms to resolve conflicts.

The research found that the service was more effective if it could offer choices or explanations about why user preferences might not be available and a respectful approach. It outlined the strategies required to overcome problems and to maximise the benefits of involvement. In particular it emphasised the need not to underestimate the investment of time and resources required to overcome complex hurdles. Strategies included:

- investing financial resources to increase the availability and accessibility of treatment and improve choice in decision making;
- improving communication, information sharing and empathy between providers and services users;
- an investment in education, training and skill development for providers and service users;
- exercising caution about pushing the user involvement agenda too far too soon with clients – some do not want it or are not ready for it; and
- an open recognition that users have unique insights into their own needs and responsibility for their own recovery to address the power imbalance.

However as one informant said, embedding involvement at the level of individual treatment can be a complex process:

> *User involvement starts in the therapeutic relationship where providers ask what the patient thinks of the service. Clinicians are not taught to work in this way or to be transparent about treatment decisions. It may be in the treatment guidelines but it is difficult to know how comprehensively it's adopted. Some do it but it's not the standardised practice it should be. We need to make the clinician confident to shift the power imbalance and it requires subtle shifts. But clinicians find it difficult to admit they are not doing things right. (Academic)*

3.6.2 Consultation and Representation

Consultative and representation mechanisms are the predominant form of user involvement. This can involve service users gathering the views of fellow service users and representing them at every level from treatment provision, practitioner forums and strategic meetings to commissioning. They include (Patterson et al. 2007):

- formal mechanisms where data is gathered in a systematic way for a specific purpose;
- informal mechanisms where anecdotal feedback is collated but the mechanism for influencing service development is not defined. These included the use of various means to engage service users in conversation like suggestion boxes, communication with key workers and so on;
- consultative meetings and open events convened to address planning issues or provide opportunities for information sharing;
- use of surveys at service level to explore specific issues; these are generally one-off rather than systematic mechanisms for engagement; and
- involvement in human resources, mainly in recruitment.

Having service user representatives can be the easiest model for providers but can also raise the issue of involving current drug-users, of timing and of representativeness. As one commentator said:

> *There are 'pet' drug users and most boroughs have ex-service users who they trot out. Users are seen as being in denial, intoxicated and incompetent and while services say if you're using drugs you're dysfunctional they also say we want you to be involved in policy. But service user reps are reluctant to disclose their using history. As a service user rep you are asked to sign a drug user policy that is stricter than for the workers and requires total abstinence. There is a general understanding that if drug and alcohol workers were tested fifty percent of good staff would fail. The current model of representation is not good. (Service user representative)*

Informants commented frequently on the timing of consultation exercises. For instance they all had experiences of being involved in establishing new services but only being brought into the process once it was underway and not at the beginning when the remit of the service was under discussion.

Finally there is the issue of representativeness where participating service users are accused of not being representative of the broader population of service users, ex-service users or potential service users. This has been used to undermine their credibility and that of user involvement work. Service user groups are aware of these difficulties and have created structures to ensure that they can claim to represent a broad range of service users.

> *Representativeness is something we bear in mind constantly. It is an easy mistake to make to think that our views are the views of everyone and not to represent the whole range from someone who smokes a few spliffs to a single mother injecting heroin five times a day and all those in-between. We do service user forums in all the local drug services and visit homeless day centres. We go out and actively seek feedback. If there's a new service coming up or a contract coming to an end and being put out to tender we collect feedback from users about what the service provided and whether that provider is worth reinvesting in. We recently did a survey about care plans – do they get a copy, is it reviewed every three months, were they listened to, were they told about other services? We have just collated that as a report and given it to the DAT [Drug Action Team] and for service users to read. (Service user group)*
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> *We visit every single treatment provider every six weeks through the community support worker and if people have any problems they tell her and she will investigate it through the advocate. We have committee meetings for all users and we have 1500 members. Every year we have an open day. The commissioner comes, providers come and we have very good discussions in workshops about gaps in services. If you are going to represent others you must do your homework. (Service user group)*

3.6.3 Peer Research

User involvement in research is a growing route for services to start user involvement processes and there is increasing attention being paid to peer research by major funders who are supporting this work. As well as providing an effective feedback mechanism for users' experiences of services and views on service developments and policy, peer research also involves users acquiring new skills, raising confidence and self esteem, increasing service ownership and improving social reintegration and employability. Types of peer research include satisfaction surveys, consultancy projects and 'mystery shopping', for example, sending in 'actors' to monitor how local authorities respond to requests for housing assistance. This kind of research is seen as having very positive outcomes and informing many different strands of services including the monitoring of gateways into services, relationships between staff and clients, highlighting good practice and improving service quality. Best practice in peer research requires training for users to impart the skills and knowledge as well as support and feedback about the findings, outcomes and results of the research.

There is now a drug user-run research and training company – the Gold Standard Team – employing only ex or current users as researchers. The Gold Team undertakes research about user involvement and is currently establishing four peer research teams on sites across the UK, each with a site coordinator. The intention is to train up peer researchers, sustain them in teams and make their services available to others.

3.6.4 Producing Information and Resources

Service users can become involved in designing and producing information and publicity and marketing resources about services or harm reduction strategies or regular newsletters for other service users. One service user group produced a guide to peer education and user involvement for the NTA (Oxfordshire User Team 2003). It has also produced a service users' charter which states that:

- treatment should be approached as a partnership with active involvement;
- service users should be treated with the same respect as staff;
- users should be informed and educated about all potential treatment options;
- urine samples should be collected in a respectful way;
- there should be no punitive sanctions for missed appointments or 'dirty' tests;
- drug user specific advocates should be available to all;

- harm minimisation should be available to those who do not want to abstain from street drugs; and
- there should be opportunities to get involved in running services.

3.6.5 Monitoring and Inspection of Services

Service users can be involved in the scrutiny and monitoring of services on behalf of regulators. The Care Quality Commission – the newly established regulator of health and adult social care in England – supports a project called Experts by Experience[14] whereby service users accompany inspectors on their visits to alcohol and drugs services. This is an approach which has been widely used in mental health, in the disability sector and in services for older people but which has only just begun in the alcohol and drug sector.

Experts are recruited from existing user groups and given initial briefings about the inspection process (Finney & Hooper 2009). Few inspectors have a detailed knowledge of the drug and alcohol treatment sector and service users can be more at ease talking to an 'expert'. It enables them to challenge the views of managers and highlight the changes required. Experts are also seen as role models by service users. As one service user group said:

> *We secured a piece of work last year for the Care Quality Commission. They have always used 'experts by experience' in all other types of services but not residential drug and alcohol services. We now work with them and go along and inspect rehabs from the service users' point of view. (Service user group)*

3.6.6 Training and Education

The involvement of service users in the training of clinicians, drug and mental health workers, health practitioners, social workers, magistrates, prison and police staff is increasingly being used to progress user involvement work and improve the quality of services. Users might also be undertaking drug awareness in schools and youth clubs or with excluded young people and educating and informing current drug users to improve outcomes. This might involve running health and harm reduction workshops, for example about hepatitis C, overdose prevention, first aid, (in partnership with the Red Cross) or the basics of the treatment system. It can also involve training in user involvement work. One service user group was generating income by undertaking user involvement training for Drug Action Teams across the country. Some service user groups have developed their own training packages as well as tapping into external programs and courses. A national user-led organisation is now offering its own advocacy course (see page 71).

> *If we can get rid of that media stereotype of a crack or heroin user and tell them the real stories. A lot of people just read in the paper about the crack head, drink driving or people going into rehab for a week and then everything is better. Our own stories humanise what a drug addict looks like. They realize there are drug users out there who are articulate, intelligent. I met a magistrate on the train and by the time we got to Southampton he had asked us to do a talk about the project as part of their training for magistrates. We have had input into the criminology degree and the feedback was extremely positive. There were comments like I was extremely discriminatory against drug users before and now I see things in a different way. (Service user group)*

> *We work with many organisations training them about their views and trying to change staff perceptions of what a service user is so they are not just a junkie but a human being who has an addiction issue which they are trying to get treatment for. You should treat them with the same respect you would a person in the general hospital. We do a twenty minute training session for new police recruits on the beat about what a service user is and what we do. We also train people within treatment services to try to get a forum started in their own place of treatment. We train them in negotiation skills, agenda setting, communication. We have three training packages about what user involvement is and what representation is. (Service user group)*

> *With funding from the police and the education authority we go into schools and give them a reality check about heroin and*

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[14] Experts by Experience was set up in 2003 by the NTA and National Institute for Mental Health in England to enable people with personal experience of treatment services to become involved in influencing and shaping the development of their own services.

> *crack addicts. This is very popular and there has also been a demand for it from parents and teachers for evening sessions. (Service user group)*

A particular concern has been the lack of any accredited courses in user involvement work and peer education and there is now a push to gain accreditation for some training packages.

Inroads have also been made into primary health care and The Royal College of General Practice (RCGP) has developed a Certificate in the Management of Drug Misuse. This is now the required qualification for GPs if they want to contract with the Primary Care Trust to prescribe for drug users and be paid for it and in order to complete their training they have to pass a paper on user advocacy. The training involves presentations and case studies that are discussed in multi-disciplinary groups and facilitated by service users. In addition the RCGP has made 12 places on the advanced course available to people from service user organisations and advocates on an equal basis. Having service users working alongside practitioners as 'expert patients' has been seen as valuable in enriching debate and tacking stigma and discrimination among GPs. However, particularly in academic institutions, progress can be slow. As one academic described:

> *The UK has well established mental health user involvement which is taught to students. But drugs is a completely different paradigm and it is difficult to get it into the nursing, social work, psychology curriculum and for academics to understand user involvement in this sector. They are also less willing to use service users as lecturers which is common practice in mental health in the university sector. Why is this, in an age where user involvement is blossoming as part of service provision and policy? (Academic)*

3.6.7 Staff Recruitment

Service users are increasingly used in staff recruitment processes. A national survey of levels of user involvement in Drug Action Teams across the country reported that service users were being used in staff recruitment by thirty per cent of providers (Patterson et al. 2007). They were seen as bringing a unique insight into what is required to undertake particular roles.

> *They bring something quite specific and different to the process. People may have qualifications but they haven't got the relationship skills and have never been properly tested in their academic pathways. This becomes obvious talking to a drug user in an interview. So it's an incredibly valuable way to involve users and improves the quality of treatment at the most fundamental level. Drug users get skills through interviewing people and you learn about how to be an interviewee. (Writer and activist)*

In order to explore the benefits and challenges and to share good practice research was carried out to document the experiences of two agencies that had been involving service users in staff recruitment for some years (Foster et al. 2007). This had included training to promote an understanding of equal opportunities, job descriptions and person specifications, assessment and interviewing techniques. It had also entailed the involvement of service users in short-listing, formal interviews, role-plays and decision-making. One organisation had established a target of involving service users in 50% of all appointments.

The research found that it was feasible to include users and allowed them to acquire new skills, raised their self-esteem and increased their sense of service ownership. It also contributed to improved decision making and quality appointments. However it did require considerable effort on the part of providers and service users to ensure it was done to a high enough standard.

3.6.8 Volunteer Work and Employment

The ultimate goal for many recovering service users is engaging or re-engaging with the workplace. The Treatment Effectiveness Strategy (see page 20) sees the provision of employment options as an essential component of holistic treatment. A major route for service users moving towards employment is through volunteer and user involvement work in the drug and alcohol treatment sector where there are recognised benefits in employing ex-users as paraprofessional staff. This can promote cultural change within services as well as increasing levels of engagement with service users because of their ability to communicate in a familiar style and to build trusting relationships. Providing occupation of some kind is also seen as a crucial element in the road to recovery.

> *The more ex users we have in services then the less there is of us and them. When there are no drug users in a service we are all talked about as 'them' – a[n] homogeneous group. But if half the staff are ex-addicts themselves they have to rethink their stance on addicts. (Service user group)*

Service user groups may recruit and use current and ex service users as volunteers engaged in delivering peer support and advocacy services, facilitating workshops, advocacy and administrative work. They may be carrying out consultations and user involvement work and doing research. This can be particularly valuable because they have unique access to those who may not be engaged with services. They may receive training about the treatment sector and local service provision, support and supervision and reimbursement for their time and expertise. In addition there are also a small number of independent user consultants undertaking research, training and consultancy work and charging professional fees.

> *We do a lot of surveys of the drug using population and most of that is done by our volunteers because they know a lot of the clients. If you haven't used class A drugs for a while things change very quickly so it's easier to have volunteers doing that sort of work. (Service user group)*

> *We have set up a network of volunteers to provide peer support and have trained former users in advocacy and mentoring. We do our own mentoring training which we have accredited. We aim to re-engage people in socialising without alcohol and they are likely to become more involved in running the service as they find their way along that journey. It can be as little as making a cup of tea for someone when they come in. (Service user group)*

However running volunteer programs can be problematic for service user groups. It can be time consuming and labour intensive to provide the support and supervision required and some groups have made the decision to transfer those wanting to volunteer to other organisations specialising in volunteer work. It can also be difficult to fund the costs of the programs. Reimbursement for volunteering and user involvement work has always been debated and user groups and others are split about whether to reward participation with training and support or with cash payments. However it is expected that organisations and groups ensure that no one is ever out of pocket and that travel and other expenses are always covered.

> *We used to take on volunteers and when we first started we had lots of motivated people getting involved which was a great help. We got them checked and the only things that would stop someone being a volunteer is if they've done a really serious violent crime. Usually, no matter how much they say they want to do, we only let them do two hours a week and see how it goes. From my experience if you are from a drug using background you think you want to get involved but once you actually have a taste of it you don't want to. The things we often need help with, like administration, is quite mundane and not quite what people thought it would be. But it's difficult to deal with volunteers because it's really a full time job in itself and we've had to think about how we give appropriate support to those who come forwards. (Service user group)*

> *We had them for a few years but I had to supervise and line manage them and it got to the point where having volunteers was proving more difficult than not having them. We work hand in hand with another organisation and send potential volunteers to them. They have a huge human resources structure that enables people to volunteer and get employment and education. We focus on what goes on in treatment. (Service user group)*

However, many providers operate policies which exclude service users or ex-users unless they have been out of treatment for two years – the 'two year rule'. The rule originated in a report produced in 1998 which suggested that consideration should be given to how long a drug user had been out of treatment before engaging in volunteer work or paid employment. This assumed that if an individual was still in treatment they had unresolved issues and were dysfunctional. It also assumed that it was not possible to be functional on a maintenance script. It made employers much more cautious about employing current and ex users in the field. It was challenged in 2002 by the NTA in order to promote the employment of ex and current users but by this time it was deeply embedded in local policies and has proved difficult to remove.

> *The two-year rule has been a real barrier to service user involvement. It's a totally preposterous rule and is not mandatory or legislated anywhere. People can fall off the rails if they're not given anything to do for two years. But without anything in place it is also detrimental. Someone can be a client one week and next week they are employed by an organisation and struggling. But we should measure it by the advances a person has made in their own lives without measuring it by the calendar. (Service user involvement coordinator)*

Secondly user involvement work has not been recognised as a career path by services in a formal and systematic way or commonly built into service user involvement models. Although service user groups and some services will employ volunteers as long as they are relatively stable and motivated, and 'on merit', others do not. To be employed in the AOD field requires a national vocational qualification which people are unable to obtain through doing user involvement work. Many would now like to see more clarity about the role of user involvement work as a formalised pathway to employment, particularly given the barriers so many ex-users face in accessing employment as the following quote illustrates:

> *It seemed to me that if I was to do something to make the biggest difference it would be to do something around drug policy as a researcher. I finished university and the Home Office had just funded a study to look at the relationship between drug treatment and crime. I got the job and on my first day I ran into a doctor who had treated me in the past and asked how I was, how was my wife and kids, wished me good luck. I told him I had spent the past five years at university and my life had changed completely. He wished me well and went off and then five minutes later two security guards came and escorted me out of the building. So the question was do I put my head under a blanket and go away? But I'm not that kind of person and the Home Office were happy for me to continue to work on the project. (Researcher and activist)*

3.6.9 Providing Services

Service users are increasingly involved as providers of services and in identifying and filling the gaps in current service provision. Most commonly service users are beginning to provide independent advocacy and peer support, education and mentoring. Service user groups may be offering telephone help lines and advocacy services and running support groups and aftercare services.

> *Peer support is such a simple thing really. If someone has a good understanding of where they have come from and what's helped them then it's really just sharing that information and giving someone a bit of hope that they can come through to the other end. Just hearing that makes people think actually I might be able to do this now. (Service user group)*

A comprehensive review of the literature about peer-based support (White 2009) outlines how these services have grown out of the failure of addiction treatment to provide a continuum of care which is accessible and affordable. They aim to improve linkages with mutual aid groups and other support by using those in recovery and can have a transforming and complementary effect on traditional systems. Like professional services peer supporters require training, guidelines and supervision. For example one service user group runs the Community Alcohol Support Team (or CAST) which operates a number of peer led support groups for current drinkers, those seeking abstinence and those who are abstinent. For many people it has meant that they do not then require treatment because they have been supported to cut down to safe levels or in some cases to stop altogether.

> *There are now terrible waiting times for people with drink problems or where drink is the main problem. There have been people who have waited so long they've actually died before they could access treatment. CAST was set up not as an alternative to treatment but as a stepping stone where people have been left out on a limb because of long waits. It's not done specifically as an alternative to 12-steps but it works well alongside it and for people who don't get on with Alcoholics Anonymous. Quite a few CAST clients were class A drug users. It's common that when people start getting on top of their drug use they start drinking and it becomes a problem. (Service user group)*

Another service user group was running a music project to fill the gaps in support once drug users were stabilised on scripts.

> *There was a lot of support for people once they first walked in off the street needing help but once they were stable, on a script, had accommodation, a lot of the support fell away. They might see a key worker every three months and a pharmacist once a week but that was it. They were just twiddling their thumbs watching day-time TV and thinking it was better being a smack head. A lot of people used to play music in bands so to give them something to do we fundraised to get some equipment and got a year's worth of funding to pay for storage and a rehearsal studio. We play once a fortnight and the target is ex users trying to get their lives together. (Service user group)*

There has been support from central government to develop a service user workforce of advocates and peer supporters. In 2005 the Department of Health awarded The Alliance (see page 71) a three-year grant to establish a national model of peer led, independent specialist advocacy provided by current, ex and non service users and carers. The aim was to help service users take control of their treatment journey by participating in care planning, and making informed decisions (Ford 2008). The Alliance appointed nine regional advocates in each NTA region to support the development of local autonomous advocacy and other user involvement initiatives. Seven current users, one ex-user and one carer were appointed. The Alliance now trains advocates across England.

One service user-led group is now commissioned by NHS Trusts to provide support groups for those with alcohol problems in the North East of England.

> *We run 15 support groups during the week and are looking to open on Sundays too. We work as an end-to-end service. You can imagine two doors and we support the person all the way through that journey and are there for as long as the person requires us. That's what I found with my time in treatment, they were giving me detox but not addressing why I was using alcohol in the first place. People come in with an alcohol problem but until we address why they are drinking we won't have much success. It's a whole new way of working with people and currently we have 580 people on our books. (Service user group)*

Another service user group has recently been commissioned to develop user involvement work in prisons as part of the Integrated Drug Treatment System (IDTS)[15]. IDTS means that whatever happens outside prisons in terms of drug treatment should also happen on the inside for prisoners. This is overseen by Primary Care Trusts. With the involvement of Primary Care Trusts comes the requirement to develop user involvement work. The service user group described the commission to develop involvement activities in a prison environment as 'an enormous challenge'.

Yet another service user group has developed an out-of-hours socially based aftercare service in one London borough. It began when two service users established a weekly badminton club in a local service. After six months and in the absence of any out-of-hours services in the borough, this developed into a weekend peer led social club designed and run by service users and offering an art club, music workshop, alternative therapies, gym and swim club. The

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[15] The Integrated Drug Treatment System aims to expand the quantity and quality of drug treatment within prisons.

club now has over 60 contacts each weekend and is supported by 65 volunteers who are both scripted and abstinent, illiterate and university educated and ranging in age from 16 to 60 years. Service users realised that they were not just supporting those who attended but were also creating a self-sustaining support network for those who volunteered. They created a team leader role through promoting volunteers who were then required to acquire management skills, participate in the management committee and undertake user involvement work with those commissioning services. A volunteer handbook was produced and the club began to write and give a series of workshops for volunteers to develop their personal skills and professional practice. They also participated in developing an accredited course covering the key skills required by volunteers to get back into education and employment.

3. Lessons for Australia – best practice models

- In the UK a spectrum of models and mechanisms for initiating, promoting and sustaining user involvement in drug and alcohol treatment services has been trialed and each has been found to have their own challenges and difficulties.

- The key message is that what is important is to design something that works for the particular client group, the staff and the services in a local area. It is not a 'one size fits all' approach.

- It is important to share good practice about different kinds of service user involvement and recognise that it is acceptable not to do some parts of it.

- It is often not the structure of the model but the spirit in which it is implemented that makes it successful or not and determines whether it is perceived as genuine or tokenistic.

4. Models of Service User Involvement in the UK

This chapter explores the development, structure and implementation of different models of service user involvement in the UK through descriptive accounts of how they work in practice. As section three demonstrated, it is difficult to outline a definitive typology because in practice different models are blurred, overlap with each other and employ a range of methods and mechanisms. The accounts here describe:

- national, government-sponsored models of user involvement;
- strategies to support the development of user involvement in local services;
- user involvement in service delivery organisations;
- service user groups; and
- national user led organisations.

Many different initiatives have developed across the country. Those outlined here would be commonly recognised as examples of good practice.

4.1 National Government-Sponsored Models

Both England and Scotland have developed mechanisms for promoting service user involvement across the country. In England this has focused on developing representative and consultation structures. In Scotland the focus has been on a national peer research approach.

4.1.1 The National Treatment Agency – National Strategy

The NTA, set up in 2001 to oversee the development of drug treatment in England, saw the involvement of service users as fundamental to improving treatment services and became a catalyst for user involvement work. It established a national, regional and local structure which shaped and controlled the way involvement was viewed, planned, funded and delivered across England (Garratt 2007). This entailed:

- a **National User Advisory Group** with elected representatives from each region to input into policy, research and performance management. (This was disbanded in 2006 because it was increasingly seen as tokenistic because the NTA failed to act on key suggestions made by the representatives).
- **regional service user forums** to bring user representatives from the Drug Action Teams together for information sharing, networking, consultation and reporting and to act as a bridge between local action and central NTA activity.
- **integrating service user involvement into NTA activities** at every level, including having a service user representative on the Board, participation on the regional panels assessing draft Drug Action Team annual treatment plans and involvement in recruiting staff.
- **issuing a policy and guidance** for local partnerships about user and carer involvement activities including recommended pay rates (NTA 2006) and an expenses policy (NTA 2005c). There is also guidance about user feedback and complaints procedures for managers (NTA 2005b).
- **establishing performance indicators** for user involvement for local Drug Action Teams.

For the past three years the NTA has also conducted a yearly user satisfaction survey built around an annual theme, for example community care planning and prescribing, harm reduction and commissioning, diversity and specialist services (NTA 2007 & 2008). This survey has demonstrated that service users are generally satisfied with treatment provision but have higher levels of satisfaction if they have a comprehensive assessment, an allocated key worker, a care plan which is reviewed regularly, a short waiting time and are treated with respect.

NTA involvement criteria issued in 2005 required, at a minimum, that services users should be involved with the Drug Action Team in the design of the local treatment system and in implementation, monitoring, review and evaluation. Now each Drug Action Team is assessed by self-measuring its performance against six key criteria which require:

- service users representative of the diverse local community to be involved in needs assessment, setting priorities and consultations on the annual draft treatment plan;
- evidence that user involvement has resulted in action at partnership and provider level;

- a partnership service user involvement strategy which includes current, ex and potential service users;
- resources and investment, including user involvement expenses and remuneration, child care and transport costs and grant aid to local user groups;
- a network of advocacy and support services; and
- service level agreements which require services to display a service user charter, to include service users in reviews and to promote access to advocacy.

How successful has this approach been? Research conducted in 2006 to quantify the level of user involvement in improving the quality of services provides the most detailed picture to date of the extent and nature of user involvement in drug treatment in England (Patterson et al. 2008). It examined the range of methods, explored the views of participants and looked at the factors that hinder or facilitate successful involvement. The research surveyed 50 Drug Action Teams selected on the basis of their self-reported progress in meeting the NTA involvement criteria and six in-depth case studies in areas reflecting the range of geographic and demographic factors that could potentially impact on user involvement.

What the research found was that operationally the approach of the NTA has resulted in the growth of locally established service user groups which are financially and strategically supported by the Drug Action Team and which comment on delivery and future planning. The research also found a number of examples where user involvement had led to or hastened changes in services and examples where it had had a positive effect on changing attitudes to the role of users. As one informant said:

> *The NTA have tried to achieve meaningful involvement in treatment. That has meant that every DAT [Drug Action Team], pretty much every project where you are proposing something new, people think more and more about how they can incorporate the voice of service users. There has been money following this requirement from the centre which means that there have been a whole range of experiments where people have tried different things at a local level – pump priming user groups, paying people to come to consultations, all sorts of things. Progressively there are more and more people involved in different forms of user involvement. (writer and activist)*

However the research also found a wide variation in the degree to which user involvement systems and structures had been established and a disparity between and within Drug Action Teams about the models and mechanisms used and how far they had been integrated into planning, commissioning and service development. Although most areas employed a range of mechanisms they were usually ad hoc and disconnected rather than elements of a strategic approach. For example, although Drug Action Teams may establish a local user group and employ a user involvement worker, they fail to ensure that users have access to expense reimbursement or training. This means the users have to withdraw because it is not economically viable to participate. Only 47% of Drug Action Teams had user representatives at commissioning level and 36% had no strategic user involvement at all.

In summary, at a national level the NTA approach has firmly established service user involvement in the English drug treatment system where it has become a standard and essential component of service provision across the country. Treatment has improved as a result and service users are now in a position where they can make their voices heard and where their experiences impact on the quality of services. Yet as some commentators point out, local partnerships still dictate the type and extent of user involvement and invite service users in rather than service users themselves dictating the agenda and the involvement mechanisms (Garratt 2007).

4.1.2 National Treatment Agency – the London Region

At a regional level the development of effective service user involvement across the 33 London boroughs has been a gradual process and evolved through experience. The service user involvement structure across London currently consists of:

- the **London Regional User Forum** meeting three times a year and open to all. This provides an opportunity for service users from across London to get involved, to network with their peers and to learn more about involvement initiatives in local areas.

- the **London Regional User Council**. This consists of nominated representatives elected through local involvement structures and meeting six times a year. It aims to create a strategic alliance between the NTA and service users in the boroughs to improve accessibility, capacity and quality of treatment. It equips its members with information about how to work with providers and partner agencies effectively while at the same time improving the NTA's understanding of what works for service users. Nominated representatives are charged with gathering the views of service users within their local partnership, feeding back those views without bias and taking information from meetings and disseminating it to service users.
- a **Service User Involvement Co-ordinators Forum**, which meets quarterly to network, share good practice and information, engage in peer learning and training and get input from the NTA. Coordinators are employed within the Drug Action Teams to develop service user involvement and inform commissioning. Posts are held by a mix of professionals, service users and, in some cases, unpaid representatives. The Forum is usually attended by representatives from one third to one half of the 33 London boroughs.
- the **London Regional User Council** Steering Group. This is a newly-developed group of six service-user members elected by Council members with a remit to plan and manage the Forum and the Council and develop a work plan which aligns the business of the Council with joint commissioning meetings in local partnerships.

This structure has had to adapt to changing circumstances and pressures to ensure meaningful involvement. For instance, originally the London Regional Users' Forum was the main mechanism for user involvement where the NTA set the agenda and disseminated information about core indicators like waiting times, retention rates and general performance management information in the boroughs. In return it received anecdotal information from service users. However commentators describe the development of an 'us and them' situation where the NTA talked and users listened and there was little truly joint work. A review of the Forum in 2008 found that its scope was too broad and a better peer learning and information-sharing environment was required. This led to the development of the Council.

Although the NTA has been prescriptive about having dedicated posts in each borough with an involvement focus it has not been prescriptive about how this should be done. All services now have a service user engagement policy and more than half of the boroughs have dedicated positions to take service user involvement forward. However overall across London involvement can be poor and patchy with missed opportunities to involve service users. For example although each borough must ensure that service users are involved in needs assessments for the annual treatment plan there is an enormous variation between them in the extent to which this occurs.

In summary developing effective service user involvement across London is a work in progress and the Forum and the Council are now targeting a number of key issues. These include improving service user involvement in the annual needs assessment process and there are plans to identify boroughs with lesser involvement levels and target them by demonstrating good practice. The NTA also wish to improve the recruitment of service users to involvement activities and improve penetration rates into populations who are not engaged with services. Lastly there is a move to improve support structures for Council representatives in boroughs. This entails developing minimum standards for the support of nominated Council representatives: for example for access to supervision, to IT and to treatment services so that they are able to represent the broad diversity of users. Boroughs are being asked to develop a supervision and support plan and to take responsibility to ensure the elected representative is linked into local support structures. The starting point for this work is a partnership audit to establish the levels of support available in each borough and whether it is sufficient to achieve the minimum standards.

4.1.3 Peer Research in Scotland

In 2003 the Scottish Drugs Forum – a national non-government drugs policy and information agency – acquired philanthropic funding to develop a model of user involvement based on peer research and focusing on improving service quality (Liddell & Brand 2008). This became the predominant approach to user involvement across Scotland.

The model involved recruiting through services groups of 6-10 service users who were drug free or had been stable for at least one month and training them in user involvement work, survey interview techniques, computing and presentation skills. The service user groups would then meet weekly and be involved in research including developing questionnaires, interviewing, data analysis and presenting the findings to policy makers in order to seek changes to services.

Peer research groups have been contracted to undertake work by planners, those responsible for commissioning services and services and to do needs assessments and service user consultations. They have also devised their own research and consultations about specific issues. For example, one group wanted to look at poverty and drug use. They found it too complex to describe the different aspects of poverty and so compiled a photographic exhibition with snaps of service users taken by peer researchers. The exhibition was presented at conferences and was described as ‘a very powerful way of getting the message across’. Peer research groups have also carried out a number of high profile pieces of research. They have been involved in the development of drug quality standards with the Scottish Government and in the inspection teams which inspect drug and alcohol services for the Social Work Inspection Agency.

The Scottish Drugs Forum replicated the model across Scotland and established user involvement groups in six different areas supported by full time development officers who maintained and developed the groups, provided a link to local and national agencies, organised training and support and administered funds. The Scottish Drugs Forum has also developed a user involvement handbook with guidelines for volunteers about user involvement work. Establishing and maintaining this model of user involvement in an urban area was estimated to cost approximately £55-65,000 per annum (equivalent to $AUS 91,000-108,000). This included salaries, travel and training costs, computers and office equipment. Ongoing funding for the work has been available through the Scottish Drug Action Teams.

The model is seen as having a number of advantages. It is able to produce a representative rather than anecdotal perspective of service user experiences which provides a firm basis from which 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. Maintaining a clear distinction between peer researchers as volunteers and their role as receivers of a service is important.

> *The individuals involved have got so much out of it and in terms of confidence and self-esteem they move on. It may be the first stage in them starting to reduce their drug use or substitute prescription and move on to education and employment. You bring them into an office environment with people interacting with them in a completely different way to what they’re used to. They were really breaking free of the service user/client relationship. That really improved their self-esteem and self-worth which is vital to do peer research. The model works because people get so much out of it. For the people still using services it gives them a bit of hope as well and they get real work experience. (Service user development worker)*

In general the model has been able to build on good relationships with frontline services that have referred potential peer researchers into the project. Indeed such large numbers of service users have been referred that it has been necessary to restrict the size of groups to a manageable number. However there have still been recruitment issues, with some services hostile to or ambivalent about user involvement and either unwilling to refer or referring unsuitable applicants. Recruits also tend to move on fast so that continual recruitment is required. And some recruits may have significant personal issues that require additional support in order to maintain the group.

> *Most people I've worked with have only basic literacy which you have to deal with before they can actually do the work. We would have to build different ways of working where we would sit down and write out what they recalled. This was labour intensive. You have to have basic literacy to cope with this work and some of the volunteers would struggle and miss information. (Service user development worker)*

Care is also required to ensure that the research continues to be based on peer empathy.

> *Our peer researchers had an average age of about 30 and you can question whether the 16-20 year age group would consider them to be peers. There were other times when a lot of the peers came from socially deprived backgrounds and if we were working in more affluent areas of the city there were questions about whether they would see them as peers because of the class difference. (Service user development worker)*

The model has had to contend with the particular difficulties associated with working in rural areas. For example the Highlands region covers one third of the landmass of Scotland and means remote villages, transport difficulties, sporadic services and issues associated with privacy and confidentiality.

> *There are big issues in rural areas, practical ones like transport and actually accessing people because they don't access services because they don't want people to know they are there. People may not want to talk about issues with people they might have used drugs with a few months ago. We did research in rural areas and had two members of staff taking peer researchers to interviews because there was no local transport. The logistical arrangements were very time intensive and costly. Groups may not want to carry out research in their own areas so you have to bring in volunteers from elsewhere. The confidentiality thing is huge. (Service user development worker)*

Lastly there have been some difficulties in ensuring that services and planners listen to and act on the findings. However peer research has been able to impact on national issues and attract the attention of the Scottish Government. Although the model has been successful in assisting people to move on there is a growing recognition that it is only reaching a small number of more stable users and that a broader and more sustainable approach is required. There is a move to further embed this model into drugs services so that support for peer researchers comes from research commissioners and funders rather than through the Forum (see below). However Scottish Drugs Forum user involvement development officers will continue to recruit, train and support peer researchers.

4.2 Supporting the Development of User Involvement in Local Services

Strategic approaches to user involvement in defined geographical areas aim to establish clear structures and processes to enable and encourage participation at all levels, from engagement in individual treatment through to involvement in policy and planning. There are numerous examples of strategic approaches. The following represent examples which are generally considered to be good practice.

4.2.1 The Service User Involvement Partnership – Scotland

This partnership was commissioned by the Greater Glasgow and Clyde Health Board and established with two year funding. In part its establishment was driven by the publication of national quality standards on substance misuse services by the Scottish Government (Scottish Executive 2006) which outlined eleven standards relating to what a user should expect of services and were accompanied by a good practice guide on service user involvement for providers (Scottish

Government 2006). This meant a sudden demand on services to build involvement into their everyday practice.

The partnership aimed to map service user involvement activity across the health board area, develop a strategy for involvement and support services to mainstream service user involvement into their daily practice. Ultimately it aims to ensure that users have a voice at all stages of their treatment and care in order to improve the quality of services. It is delivered jointly by two non-government organisations - the Scottish Drugs Forum and Alcohol Focus Scotland.

The partnership spent the first nine months mapping all substance misuse services to look at current involvement practice and to develop a work plan. The mapping found 77 services in the area ranging from counseling to residential rehabilitation and inpatient services all with varying levels of service user involvement. Most had some involvement activities built in but all identified a need for further developments in this area in order to meet the demands from those responsible for commissioning services, funders and inspection agencies to demonstrate involvement activity.

Through five development staff, the partnership advises, trains and supports providers to develop new mechanisms for service user involvement from individual care planning to ways of ensuring involvement throughout organisations. It is not prescriptive and responds to individual providers' needs. This might entail users being involved in staff recruitment or sitting on management committees, designing a satisfaction survey, or assisting with the setting up of a suggestion box. It also offers a one-day training package tailored to the needs of individual services. The package incorporates users as trainers and covers staff awareness and understanding of service user involvement and its history within the organization. It aims to break developments down into very practical step-by-step exercises and produce an action plan for the development of involvement activities within the service.

There have been some challenges working in rural areas especially as service users might have significant distances to travel to participate and this has required thinking creatively to cover the resource implications. The main challenge however has been in identifying the key people to work with in different areas and services.

The funding for the partnership is considered to be minimal – salary and office costs for five workers. There was a deliberate decision not to have a budget within the partnership for setting up involvement activities so that providers, planners and policy makers would take ownership of involvement and develop the structures, capacity and resources to embed it rather than relying on others to do it for them.

4.2.2 A Strategic Approach in One London Borough – Croydon

Croydon's model of service user involvement is generally regarded as a model of good practice and it has had positive endorsement from service users, service providers and from those responsible for commissioning services.

A Service User Representation Group (SURG) was established in 2004 to coordinate and guide the development of service user involvement in the borough. It is chaired by the Drug and Alcohol Action Team and its members include a representative from each of the core substance misuse services as well as service users. In 2005 Croydon Drug and Alcohol Action Team in partnership with the SURG adopted a toolkit which had been developed by the International Centre for Drug Policy (ICDP/Croydon DAAT 2007). This has become the framework for involvement work in the borough and outlines the corporate approach of services in Croydon on how to involve users in alcohol and drug services. It acts as a guide for managers in the statutory prescribing service and in community and residential services to assist in developing their own service user involvement policy.

Each service provider is encouraged to:

- outline a service user involvement strategy and action plan for involving users;
- identify a nominated person to take the lead on involvement issues and act as a 'mentor' to service user representatives who are current or ex users of services. The lead is responsible for supporting and monitoring their participation through six-weekly

supervision and ensuring they are consulted about proposals for services;
- implement different methods of engagement – suggestion boxes and feedback forms, questionnaires, service user groups, interview panels and peer educators;
- provide a package of support to service user representatives including the reimbursement of expenses and the other tools necessary to facilitate involvement – working space, access to computers, telephone and email.; and
- prepare an annual report on these activities.

The views from the service user groups are fed up to the Drug and Alcohol Action Team via the SURG to inform the way in which local services are delivered or organised. The SURG meets quarterly to guide the development of involvement activities against an agreed work program.

Additional support and guidance is provided by a Service User Involvement Coordinator employed by Croydon Drug and Alcohol Action Team. The role of the coordinator is to raise the profile of involvement, support services with their methods, and deliver and arrange training. Monthly forums for service user representatives and for mentors are facilitated to provide them with support.

The model is currently provider rather than user-led but aims to protect service users from burn-out and relapse and to manage their expectations. It ensures that a range of views are heard through a spectrum of consultation mechanisms employed in local services. It also recognises the importance of training and support for service users and is flexible and adaptable as lessons are learnt and new needs identified. The model does rely on providers engaging service users and getting providers to do this was an important development process that took several months. The role of the 'mentor' can be difficult for workers in practice and it can be hard for them to find the time to undertake the work. Efforts have been made to make 'mentoring' integral to a worker's role so they do not have to do extra work. However overall it has been a slow process of raising awareness and understanding. As the service user involvement coordinator said:

> *When I was first in post I went round to all the team meetings and gave presentations and an overview of my role and the benefits and challenges of involvement. The statutory service in Croydon provided an office area for reps so we started to use it regularly for peer support, talking to people or smoking cigarettes with people outside. From actually going and doing it the key workers started to see the benefits and now they are happy for the reps to be on site giving peer support because they can see it's added value and that it's not something they have to manage which takes time away from their clients. It's a fear factor where they think reps are going to run riot or relapse or not be professional. They have developed various attitudes from seeing chaotic clients. When people see them acting professionally - and not sitting swearing and not understanding what's going on - then it does change people's perceptions. (Service user involvement coordinator)*

Getting staff on board is only the beginning of the process and moving from there to actually getting service users involved in decision making is again a slow process of building trust and calming fears:

> *One service is quite happy to meet with reps, have them giving advice and information about the service, let them facilitate a service user group and help with an agenda. But when it comes to a decision about the service that they discuss in a team meeting they won't have a rep in there, it's a step too far. For example in one service there was an issue with people hanging around outside drinking and smoking and rowing. The reps said they would speak to them peer to peer. What I said to the service is that it would be helpful when discussing this as a team not to have the discussion and decide things and then speak to the reps but to invite the reps into the team meeting at this point. One drop-in service had been letting their clients use the phone and the internet but they found people phoning their dealers or phoning abroad or using inappropriate sites on the net. They had a discussion in the team meeting and came out and said no you can't do this or that. They could have included the reps in that discussion*

> *and they would maybe have had some ideas about it. It's a shame to bar all calls because people use them to phone about benefit appointments or housing. They should have been supervised. A reason often given for not inviting reps in is that it's confidential. So don't invite them in for the confidential bit. It is changing and they are being invited into team meetings but it takes some getting used to and they think the service users are going to take control. (Service user involvement coordinator)*

Statutory services (services that are required to exist by law) can find it particularly difficult.

> *The care management team have said things like "we can't see how we could involve someone in our service because we are not that sort of service". There is always the stigma of substance misuse and the fact that everyone sees them as being intoxicated and unable to string two sentences together. I suggest if you are going to write a leaflet about your service you can involve clients in designing it. They say we don't do leaflets about our service and I think perhaps you should. (Service user involvement coordinator)*

Challenges include service user representatives relapsing, the need to continually recruit new service users as people move on and how to better consult with those not engaged with treatment services. The latter has been tackled by conducting one-off survey work in needle and syringe programs and hostels for homeless people.

The model gives some consideration to the pathway from service user representative to volunteer work, training and paid employment. People generally want to get involved in order to give something back and to help other people. The confidence and skills they learn along the way can be applied to other areas of their lives and look positive on a resume.

One of the most significant consequences of the model has been the establishment of peer-led aftercare[16] in the borough. A review of services by an independent consultant highlighted the lack of aftercare in Croydon and collated the views of service users about filling this gap. What people wanted to see was a group run by peers and outside mainstream services. A group was established two years ago, with funding from the Drug and Alcohol Action Team, to provide peer support, social activities, free gym membership and access to various training courses. It includes families and also operates a social club. The service is abstinence based and not for those actively addicted but it operates outside of the traditional Alcoholics Anonymous and Narcotics Anonymous network. In addition there is Croydon Peer Led User Group (or PLUG), also set up as a drug and alcohol free space by service users in response to the gap in the aftercare options. PLUG receives £8,000 per annum (or about $AUS 13,000) from the Drug and Alcohol Action Team and has a weekly meeting, a monthly social club and trips and social events. It provides mutual support and acts as a user voice by contributing to consultations about treatment services. Up to 200 people have been involved in PLUG in the past two years and it is now hoping to develop into a social enterprise.

Those responsible for commissioning services in Croydon have been very positive about the benefits of the model and consider that the involvement of service users has 'changed the face of commissioning':

> *We have formally worked with reps on contractual development and tender processes. I found their input to be invaluable particularly as they are able to get to the bottom line when assessing new services and forecast the usage of new services. For example, they are able to tell commissioners where service users will try to buck the system. They are also a great indicator of what is missing from services. They have the capacity to act formally as regulators to both DAATs [Drug and Alcohol Action Teams] and local services and are very good at assessing risk – a core function of any regulatory process, for example, assessing and developing double scripting controls, recognition of issues around prison release clients, delivering harm reduction training and so on. If I were to develop an agreed understanding of what service user rep specialisms are, risk management would be one of the main*

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[16] Aftercare refers to services providing support after being discharged from formal, mainstream treatment services.

points incorporated. Overall I find service user reps to be incredibly talented in what they do. Their contribution always adds value and in a perfect world they would be the commissioners rather than ourselves. (Service commissioner)

One commissioner identified a number or core elements which need to be in place for effective user involvement to flourish:

- A period of adjustment is necessary for service user involvement to be accepted by providers and so that they are able to recognise the specialist expertise which users offer. Providers can be anxious that service users see service potential in an idealised way with no thought about budgets or capacity. There are also limited opportunities for service users to demonstrate their value to agencies which results in a vicious circle.
- Over time service user representatives become exposed to all the issues that regulators face. As their knowledge of service constraints increases their empathy gravitates towards the agency perspective rather than retaining the service user experience. Access to remuneration and financial gain can also colour users' contributions over time. A 12 to 18 month change over period for representatives would maintain a service user focus and avoid these difficulties.
- There is a self-esteem issue that often makes it difficult for service users to see the value in what they add to local services and promotes a reticence to speak up in meetings. A secondary issue is where new representatives dominate meetings due to their unfamiliarity with corporate processes. Managing this is a formal piece of work that needs to be incorporated into any service user involvement strategy.
- Activity at all levels, including national, and 'joined up' involvement across the service tiers is the best model. The strongest model is a service user board where the Drug Action Team has to respond to their concerns and take the service user seriously.

The Croydon model illustrates how essential structure is to effective user involvement work even though the best practice often emerges organically over time.

4.2.3 Service User Involvement Project for Substance Misuse – Brighton and Hove

In 2004 Mind[17] was commissioned by Brighton and Hove City Primary Care Trust to run a series of public consultation events with local substance misuse service users. Subsequently Mind successfully tendered for a contract to develop service user involvement across the Primary Care Trust area and a Substance Misuse Service User Involvement Worker post was created. Using the experience of good practice in involvement activities and consultations with service users an involvement strategy for substance misuse was developed for the Brighton and Hove area in 2006 to provide a framework to promote involvement work.

The strategy contains clear guidelines and goals for service providers and those who commission services and is written in user-friendly language. It includes a statement of the purpose and principles of service user involvement and guidelines about engagement, methods, resourcing, training and monitoring and evaluation. It is all-encompassing, ranging from policy work to involvement in care planning. Although it took some time the strategy is now embedded in the sector and all local providers and commissioners are signed up to it. Providers are required to give evidence of service user involvement at all levels, to have an involvement policy or strategy, to inform users of the right to be involved and to welcome them as job applicants. They are also required to involve users in designing literature and information resources, in staff recruitment and training and consult them about any changes to services.

Service user representatives and service user groups and forums take part in contract monitoring and reviews and strategic planning meetings. Service users sit on the Joint Commissioning Group and the Treatment Performance Group that looks at key performance indicators, outcomes and treatment monitoring. They are also consulted not just about treatment but on wider aspects like clinical guidelines and residential services. They have participated in developing and delivering training for service providers and commissioning organisations about good practice in involvement activities. This has

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[17] Mind is a leading mental health charity in England and Wales which aims to influence policy, challenge discrimination and promote the development of quality services and inclusion.

involved recruiting and training a team of five user-trainers. An annual consultation with users helps to identify service user priorities for the adult drug treatment plan.

> *It's effective because every single service provider is not just signed up to the strategy but they are also signed up to the service user involvement reference group which happens every couple of months. That means there is an elected representative from every provider or organisation from all three tiers – from open access, from prescribing, from residential – who comes to that group to address involvement within their services. They are all signed up to the strategy and they have their logos on it and work with us. We are able to roll out all those levels of engagement whether its making sure the services have got forums in them, or members of staff ensuring every service user has a care plan. Because they are signed up to the strategy we are able to enforce it and if it's not being done I am able to go to the service, talk to the manager or director and say do you need some help with that? What can I do? That's the way we work. (Service user involvement worker)*

The service user involvement post also provides practical support to a number of service user forums and groups in provider organisations including day programs, a street drinkers' group, ambulatory detox, the harm reduction service, rough sleepers and a number of other community services. A service user involvement leaflet has been developed explaining how to get involved. It is distributed via services through posters and put into treatment packs for all clients. There is now a concern to get under-represented groups like black and ethnic minorities and gay people involved and to push for improved wraparound services.

Peer based recovery support has been a growth area in the region with peer-led groups doing relapse prevention and recovery support. Most recently funding has been allocated to improve the uptake of aftercare support for offenders on their release from prison. This entails training current and ex-service users to pick up people leaving prison or coming out of treatment and act as 'buddies' to smooth their path into support groups, training, education and new social environments. As the involvement worker said 'it's about showing people what's available out there and that they don't have to return to the same group of people they used to hang out with and who got them into trouble in the first place'.

Although funding for the project focuses on drug misuse and omits alcohol, as long as a service also embraces drug issues the project can address alcohol problems. This has recently become easier with new funding for alcohol projects which target harmful and hazardous drinking.

The Service User Involvement post holder attributes the success of the strategy not only to having national and local requirements that providers have to meet but also having good working relationships, a body of service users who want to be involved, being based in an organisation independent of the treatment sector and having a comprehensive strategy which is credible.

> *If you have a good relationship and it's obviously for the benefit of service users and providers to get treatment and delivery right then everyone is going to be on side. If people don't understand what service user involvement is and think its just going to cause complaints or more work then you are going up against a brick wall. So it's about working with providers and developing your own personal relationship with them. I constantly see them and work with them to address issues, but in a positive way where we can work together and not just appoint blame and point the finger. I found services were calling me up begging me to come in and when you have that kind of climate its much easier. It works in Brighton because it's credible and if you're going to do it you need to do it credibly. There are a lot of people in Brighton who say I don't care, I just want to get my bottle of methadone or my pack of needles. So you also have to have the strength of opinion within the user body and people who actually want to be involved and to have a voice and the right people to take things forward. If you have the wrong person leading because they are very angry and it's*

> *all about blame and complaining, you're off on the wrong foot already. (Service user involvement worker)*

The strategy and its implementation represent a model that could be tailored to many different environments and demographics.

4.3 User Involvement in Service Delivery Organisations

Alcohol and drug services have a legal duty to implement service user involvement through the 2001 Health and Social Care Act. They may also be receiving funding from Supporting People[18] and the NTA, which ties them to the national standards on service user involvement. In local areas the specifications or service level agreements for providers will usually stipulate that services must have service user involvement that links in with the local service user representation structures through the Drug Action Team or borough so that there is engagement at both a service and a strategic level. Larger organisations running programs and services across the country may have a corporate involvement policy or strategy that is then implemented locally in each service. It is generally considered that good practice in service user involvement should range from having a say in the choice of biscuits to having input into corporate development plans with all levels of participation equally valued.

Implementation of these requirements has been erratic. An investigation of existing levels of user involvement in selected community based drug services across Northern England (Schulte 2007) found low levels of involvement with 16% of services having none. It also found discrepancies between service users' and providers' views about desired levels of involvement and priorities for service development. Service users wanted higher levels of involvement, a reduction in waiting times and an increase in staffing and counselling services. Providers on the other hand had low aspirations for the benefits of involvement and wanted an increase in complementary therapies and staffing. Overall the research found that user involvement is still under-utilised in current service provision despite its potential benefits.

However a number of the larger providers have been demonstrating a strong commitment to implementing service user involvement and adopting innovative approaches organisation-wide. For many of them this represents a move away from ad hoc, informal approaches to creating embedded formal structures which can sustain involvement.

The following descriptions use data from interviews with those responsible for developing user involvement activities, from strategy and policy documents and from first hand accounts by service users.

4.3.1 Addaction

Addaction is one of Britain's largest community sector specialist alcohol and drug agencies providing services to over 25,000 people in 70 community based services. It has been identified as being in the forefront of the substance misuse sector in developing an organisation-wide service user involvement strategy giving users significant influence over policy and service delivery.

Until two years ago local service managers were responsible for developing involvement activities but with no corporate strategy or policy. In the absence of any specific NTA measurement tools, the question of whether services were reaching quality standards in this area was determined by self-reporting. This meant that user involvement could be portrayed as being alive and well without it actually being a reality. Addaction concluded that their approach was tokenistic and in response appointed a Service User Involvement Coordinator. The post-holder was an ex-service user and activist who had been undertaking consultancy work with Drug Action Teams to set up user involvement mechanisms and support the development of service user groups. The post-holder's first task was to explore what Addaction was doing wrong and why involvement activities had not been as effective as they might be.
This led to the production of a report that was disseminated to all Addaction services. The report became a starting point for engaging all services in a debate about how to make things better and how to promote the cultural change required to achieve this.

A National Forum comprising 12 current, stable

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[18] The Supporting People program, established in 2003, provides housing related support services to vulnerable people.

users was established to develop a service user involvement strategy with a base line, targets and measurement tools. Selection to the Forum entailed a rigorous short-listing process based on set criteria and an interview. As the coordinator said ‘it is not enough just to be angry with services’. The Forum has a place on the clinical governance working group alongside directors and trustees. It is anticipated that when the confidence of the Forum increases they will attend Board meetings and have a direct impact on national policy.

There were no problems in recruiting to the Forum and the selection process entailed turning a number of people away. In order to be able to draw on this interest and promote wider engagement a system of peer champions was established to encourage further involvement in local services. Anyone can become a peer champion as long as they demonstrate ‘a level of personal stability’. Their role is to:

- meet and greet new clients;
- participate in workshops to produce user friendly information leaflets about the service, for example, about substitute pharmacotherapy;
- conduct monthly consultations with service users with themes set nationally, for example, the convenience of the service. These consultations are undertaken in waiting rooms using a simple questionnaire and provide continual feedback from a wide range of service users.

The concept of peer champions is currently being piloted in ten sites across the country with up to five champions in each site. The sites cover the range of services including residential services and projects in prisons. Training and support needs are identified and met through a centralised training budget and include presentation skills and how to host consultations. Meeting the training needs involves both tapping into external training packages and developing in-house training for peer champions. There is also training for staff about what user involvement is and input into the staff magazine about involvement activities, with a requirement for staff to discuss involvement at monthly team meetings.

The model as it is developing is not expensive. Nationally, costs include the coordinator’s salary and on costs together with a budget of £20,000 for the National Forum, a total of approximately £60,000 (about $AUS 100,000). Supporting peer champions locally is covered by service level user involvement funds built into contracts with local Drug Action Teams.

Drug Action Teams in the pilot areas have welcomed the service user-led consultations and have participated in defining themes and questions. This approach has already led to radical change within the organisation. This has included the Forum rewriting the complaints process and redesigning client publicity about it to better empower service users to complain. Developing this approach has not been without challenges and as the coordinator said it required courage on the part of the organisation to carry it forward and champion it:

> *It is very scary for the Board. If the only feedback is negative and shows that the organisation is bad, this would be bad for staff morale. But they have been very receptive to comments and one factor was having a chief executive who was really behind it and, as the results came in, becoming even more behind it. (Service user involvement coordinator)*

It is anticipated that the Forum will grow in influence and in driving the organisation strategically. It is also anticipated that an intermediate level of regional forums will be established and that the peer champion approach will be rolled out nationally. There is now a concern to develop user involvement activity as a career path by getting as many service users involved as possible and connecting them up to generic training so that they can transform from being a service user with a negative history to someone with employment prospects.

4.3.2 Foundation 66

Foundation 66 works with people with problematic alcohol and drug use and their carers and families across the London region. It provides treatment (including residential rehabilitation, counseling and detoxification) and aftercare services including temporary housing, tenancy sustainment and resettlement support.

The organisation's user involvement work began in 1999 (prior to the advent of the NTA) with the establishment of a steering group of staff and service users who met over a one year period to discuss the aims and objectives of user involvement. This resulted in establishing a model with a central council of self-nominated service users supported by an involvement coordinator. By 2002, although there was a Council of eight service users involved in governance issues and influencing the Board, internal conflict led to its demise. It was re-established in 2004 with new recruits and renamed Advisors to the Board. However there were still concerns about its representativeness and lack of ongoing consultation mechanisms with service users.

In 2007 a Central Service User Council was set up to advise the Board on policy and service development but this time with consultation mechanisms built into the structure and an agenda led by service users. Each Council member undertakes to do at least one service visit, ideally two, per month to consult with users and feed back to them about any Council business and policy changes. The Council meets monthly with the Chief Executive prior to Board meetings and members of the Council attend the operations subcommittee, finance committee and Board meetings. It is intended that the Council be involved in as much as possible, including attending staff away-days and NTA forums. Council members tend to be those users living in the longer term residential houses and the average length of service on the Council is six to twelve months. Members are given monthly supervision by the involvement coordinator.

In order to increase the numbers of service users involved beyond the Council membership a series of groups are also being established. They include an activity group to plan events and recreational activities, a gardening group offering services to the 20 residential homes, and a policy and practice group dealing with health and safety issues. There is a Green Group looking at environmental issues and a diversity group looking at diversity policy. It is hoped to develop a pathway so that service users can progress from client services meetings, to groups and on to the Council. In addition there is a quarterly service user day open to all where users can discuss issues of importance to them and a monthly service user newsletter where users contribute articles. Service users are offered training about how to make meetings work and building confidence and assertiveness. They also have access to a one year National Vocational Qualification in health and social care for those aiming to work in the alcohol and drug sector. Integral to the model is the development not only of user involvement mechanisms but also the dual aim of developing the skills of individuals.

This model of user involvement costs approximately £60,000 (about $AUS104,000) per annum which includes the coordinator's wage and a budget of £10,000 to cover expenses. In addition there is cost of the time spent by service staff in facilitating involvement activities as well as printing costs. The organisation has a policy of no monetary reward for user involvement work beyond reimbursement for expenses. This avoids problems with the benefits system. Users however have access to gifts, vouchers and training. In future the Foundation hopes to increase the number of service visits being undertaken by Council members, establish annual user surveys for every service stream, and develop the work of the Council through a quarterly newsletter for clients. It is also hoped to produce training packages and toolkits for feedback and complaints handling as well as encouraging client participation in staff recruitment.

4.3.3 Garrow House, Turning Point

Turning Point provides over 200 services across England and Wales for people with complex needs including those affected by drug and alcohol misuse, mental illness and learning disabilities. In the substance misuse field they provide drug and alcohol services, residential detox and rehabilitation and needle and syringe programs. Garrow House is a high support 12-bed residential service providing supported accommodation for up to three years for women with complex needs leaving secure services that offer high levels of care in restrictive environments.

Garrow House opened in 2009 and its design was shaped by the views of service users. This was progressed by the involvement lead from the local commissioning team who started a project called What Yorkshire Women Want. In this project women in secure services across the region were consulted about what they needed from a 'step down' service and their responses were incorporated into the building design and the development of the care model at Garrow House.

User involvement is now interwoven into every aspect of the service and service development by ensuring that there are many different ways in which to get involved. These range from involvement in individual treatment and care plans through to service delivery and regional policy. There is a project involvement worker whose role is to coordinate and promote involvement activities rather than taking responsibility for them. Mechanisms include both groups and one-to-one meetings and having a resident involved in staff recruitment, short-listing and interviewing. This has proved particularly valuable as residents' feel for a person and their knowledge of how that person would fit in has been astute. There is also involvement in developing policies and risk assessments.

> *A typical week of user involvement comes in many different guises so each individual can have a level of involvement. I run a women's involvement group on Wednesdays where I share coming involvement events. We have three clinical governance meetings – one for the women and staff, one for the staff and one for the organisation. A representative from the women's group sits on each one. We have a steering group with a women's rep who feeds back to the community. We have taken involvement into the core of our ethos and it happens every single day by every single member of staff and every woman. We have learnt a lot from bringing women into potentially confidential situations. That responsibility can be difficult but it can also be extremely empowering. We never discount anything a service user says to us and are guided by the women. We are working towards user involvement being everyone's responsibility. (Project involvement worker)*

As the project involvement worker said 'involvement has become a discipline in its own right, like multidisciplinary working or nursing or occupational therapy. It has to be viewed like that to have a true run and to be meaningful'. The Garrow House model represents a shift from seeing involvement as an add-on driven by a few enthusiasts to an integrated service-driven process.

4.3.4 Equinox

Equinox is a specialist care organisation providing residential and community based services across London and South East England. It originated in the mid 1980s to meet the gap in services for homeless people with substance misuse problems, primarily alcohol. It has grown since then to support over 6,000 people each year who have complex needs, drug and alcohol problems, mental health issues and often criminal records. It provides alcohol and drug treatment including detoxification units, wet hostels[19] and supported housing, community services and mental health services.

Although the organisation had encouraged service user involvement the responsibility for working out how best to find out what users thought and to involve them had remained at the local service level. Mechanisms had been developed such as breakfast meetings and service user representative positions. Ex-service users were involved as volunteers and the views of service users were being incorporated into corporate planning at an organisation-wide level. However overall this had led to an ad hoc approach to involvement across the organisation and a need for a central push was identified to provide training and guidance on good practice in involvement activities and to address the gaps at an organisational level. A service user involvement manager was appointed in 2008 to work across the organisation and develop a three-year strategy and action plan to facilitate the sharing of experiences, to ensure consistency of standards and to allow the development of the monitoring and measuring of service user involvement.

Equinox developed a service user involvement strategy (Equinox 2008) in consultation with all stakeholders including those external to the organisation. Prior to the official launch of the

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[19] The term 'wet' refers to a service which accommodates both the drinker and the drinking and recognises that at the point of entry into the service the individual is unable or unwilling to contemplate life without drinking.

consultation current service user involvement practices were mapped against the standards required by funders in order to identify good practice and gaps. This meant visiting all the sites and meeting with providers, service users and Drug Action Teams. It also meant conducting a literature review about good practice. The mapping exercise highlighted that it was problematic to consult on service user involvement until there was a basic awareness of and structure to support it already in place. This led to direct work to raise awareness and stimulate the development of involvement in individual services appropriate to the needs of their particular service user groups.

The strategy consultation used a range of methods including a user-led event, focus groups, questionnaires and themed workshops and was designed to exemplify good practice in service user involvement. Over 190 service users, staff, managers and other stakeholders took part. The consultation found that service users wanted accessible information about their rights and responsibilities, informal activities to encourage engagement, peer support and a better knowledge about involvement activities. They also wanted access to training, policies and procedures, rewards and recognition and opportunities for involvement at all levels and highlighted the importance of being listened to. Staff wanted more knowledge about the benefits of involvement and the funding, resources and time required to facilitate it. They wanted assertiveness and communication training for users and were concerned to avoid tokenism and to ensure that any central structures and systems took into account the diversity of services and did not inappropriately attempt any 'one size fits all' approach. Those responsible for commissioning services wanted to see a strategy with real teeth and to see service users attending local strategic forums more regularly. They also wanted Equinox to be more user-led and to meet targets around involving service users in contract reviews and recruitment.

What emerged from the consultation, and in particular from the consultation launch event, was a strong commitment to involvement from service users, senior managers and Trustees. A first draft of the strategy was put together by the service user involvement manager based on the priorities identified by service user representatives. The draft was taken back to the representatives for review, amendment and final approval before being presented to the Equinox Board of Trustees. Key findings from the consultation were that there was a need to develop:

- a greater awareness of what service user involvement is and why it is important;
- guidance on what constitutes good practice in involvement and tips for putting it into place in particular services;
- structures for facilitating direct feedback between service users and senior management; and
- greater partnership working between staff and service users.

A vision was developed alongside a service user involvement toolkit about how to achieve the minimum standards. It is proposed to establish a framework for a central service user council which will include reward and recognition policies and systems for supervision and recruitment and which will acknowledge the diversity of services. All working groups and staff recruitment processes will include service user representatives. The strategy document includes a timetable of activities over a three-year period with monitoring of activities and a final review and evaluation. Unlike other organisations Equinox has decided to pay the minimum wage for involvement activities rather than reimburse users solely with gifts, vouchers or access to training.

Activities include reviewing the rights and responsibilities charter, the complaints procedure and policies on confidentiality and vulnerable adults with service user input. It also includes ensuring every service user has access to independent advocacy. All services will be required to have a written involvement procedure and action plan and to have activities included in service budgets. It is intended that project workers should have access to training in service user involvement and service users to training in communication skills as well as specific training for user representatives to support them in their roles. The impact of this on service delivery will be reviewed.

At an organisation-wide level implementing user involvement will entail establishing clearly defined communication channels between users and senior managers and including them in central decision making bodies. There will be training for senior management and the Board and the skills requirements for recruitment to the Board will include the experience of using services. A joint human resources and service user involvement working group will be established to review policy and procedure about involvement in recruitment, to identify staff training needs, to deliver training and to feed into staff appraisals.

4.3.5 St Mungo's

St Mungo's is an organisation that houses, supports and cares for vulnerable and excluded people who either have been or are at risk of homelessness. It runs over 100 projects across London and southern England. It is officially committed to service user involvement at every level and sees it as a pathway for service users to gain confidence and experience and to empower them to move away from dependence on services.

For many years St Mungo's had informal service user involvement but no formal structures. A review of the barriers to engagement conducted by an external agency and controlled by service users identified an organisational receptiveness to change and this led to the establishment of *'Outside In'*. *Outside In* is a client led network within St Mungo's with an active core group, a general membership and a non-hierarchical structure and committed to a recovery-based ethos. All clients are members with a right to attend the monthly general meetings, raise concerns and issues, put forward ideas, influence the agenda and vote. If clients can commit for a minimum of one day a week they are eligible to sign up as 'active members' or volunteers. Active members sign up to a Code of Conduct, are subject to the same checks as staff, are given access to the IT system and are trained as peer facilitators so that they can support other residents to run their own meetings. They run presentations and workshops at staff inductions and help in the recruitment of new staff. Overall the model aims to transform members' lives through self-determination and personal development and, as one informant said, 'ensure that the experience, skills and talent of St Mungo's clients are recognised and utilised in tackling the problems that St Mungo's and the client community face'.

There have been challenges in engaging service users who are only in contact with St Mungo's for a brief period and when there is a high turnover. This requires engaging more quickly and effectively than when there is a longer-term involvement with the organisation. Once clients move out of St Mungo's services they can still be active members for six months. After that they have the option to become a St Mungo's volunteer.

Initially there were many concerns about representativeness and tokenism. This ultimately led to a realisation that what had been identified was a long list of why service user involvement was not possible. There is now a client representative sitting on the Board and ten times a year *Outside In* meets with the directors of St Mungo's with an agenda agreed at the general meeting. Delegates are rotated in order to give all who wish it a chance to attend and there is also an annual client conference. All expenses incurred during *Outside In* business are reimbursed. Otherwise work for *Outside In* is done on a voluntary basis.

There are concerns that peoples' right not to get involved must be defended while equally clients should not become professionally homeless or professional service user representatives. This means that user involvement is always seen as aiming to transform lives rather than about being a service user with the emphasis placed on moving on. If user involvement is only seen in terms of improving the quality of services then big opportunities are missed in the transformative impact on personal development. This means that it must always involve pathways, for example into employment.

The benefits of the model for St Mungo's have been about formalising accountability to service users, providing occupation, giving a creative edge to designing services and focusing minds on citizenship. This has included encouraging service users to stand in local elections and lobby politicians and a drive for voter registration. Overall user involvement activity has become a springboard for many other developments and activities while also allowing the organisation to meet its targets in terms of promoting user involvement and improving services.

St Mungo's now offers client involvement training and a toolkit to other organisations. The toolkit covers how to involve clients in business planning, improve resident meetings, run focus groups and facilitate peer mentoring as well as how to enthuse staff and involve the wider community.

4.4 Service User Groups

There has been a major growth in service user groups in the past few years and they have proliferated across the country. There is no official or formal procedure for collecting information about them but they range from a handful of people involved in improving local services to larger NGOs with paid employees lobbying at a national level. They may be involved in developing local drug policies, harm reduction interventions, educating service users about their rights and treatment services, training practitioners, providing peer support and alternative support services, campaigning and producing and disseminating information. They might be specifying and assessing tenders for services, acting as treatment watchdogs, leading consultations with users and building capacity by sharing skills and good practice with other organisations. Some are providing a career path through volunteering, peer support and user involvement work into paid employment, education and training. A service user group might be nurtured by the treatment system as part of a process of involvement but become independent with its own agenda and work outside existing provision to promote change. In practice most user groups are run and owned by Drug Action Teams or community drugs teams and treatment centres. They can have an influential impact on services, represent a wide range of views and have unique access to those who are unengaged with services.

The researcher interviewed key informants from a number of service user groups around the country who would be considered to be examples of good practice. That means that although they would not necessarily be typical they would share a number of the characteristics with other user groups. Informants were asked to describe how the group first got off the ground, the legal status and governance and its aims, operation, activities and funding. They were also asked about what kind of impact they had had on local services, the difficulties and challenges they had faced and how they would like to see the group developing in the future. The groups were:

- **Morph**, an independent grass roots organisation started and run by ex and current users and operating across Southampton, a city in Southern England with a population of approximately 234,000 people. Morph provides an advocacy service, a newsletter, *Morphin*, weekly drop-in sessions offering peer support, a resource library, workshops on hepatitis C and overdose prevention, service user consultations and representation on committees and decision-making bodies. It has now been commissioned as an independent service by the Drug Action Team to work in partnership with the drug treatment system locally. The annual budget is approximately £70,000 ($AUS121,000) with most of that being wages for two workers and the costs of the auspicing organisation – Southampton Voluntary Service – which provides office space, supervision and payroll services. In addition Morph raises another £10-15,000 per annum to run other projects and the newsletter.

- **Oxfordshire User Team (OUT)**, established in 2002 and working across urban and rural areas in Oxfordshire and Buckinghamshire in South East England. OUT evolved from peer education sessions which then became a forum for conducting consultations with servicer users for local treatment services and the Drug and Alcohol Team. It became an independent charity in 2003 and now provides a user-led system of involvement through three full-time staff – a coordinator, harm reduction worker and project support worker – funded by the Drug and Alcohol Team and supported by eight volunteers.

OUT runs peer education workshops and provides peer support and advocacy, produces information and resources, delivers training to users and providers, runs a volunteer program and is fully involved in the planning and commissioning process for services locally. It supports other existing groups and has worked with the NTA to set up user groups all over the country. For two yeas it held a contract with the NTA to deliver training to five Drug and Alcohol Team areas per year. It now holds a number of training and user involvement contracts and receives approximately £90,000 ($AUS156,000) per annum from the local authority in Oxfordshire and Buckinghamshire.

- **North East Regional Alcohol Forum (NERAF)**, set up by a recovering alcoholic when he discovered that the only support available to him was Alcoholics Anonymous. He started a support group in his own home which has grown into a large alcohol specific peer-led service operating from four different buildings with fifteen staff. NERAF is now an independent charity based in Sunderland and commissioned to provide a network of support groups across the north east region with funding of £450,000 ($AUS800,000) per annum. It has recently been commissioned by the local NHS Trust to replicate the work in neighbouring areas.

- **Bournemouth Alcohol and Drug Services User Forum (BADSUF)**, an independent user controlled organisation providing support and information and giving a voice to service users across Bournemouth, a large coastal resort in the county of Dorset. BADSUF was first established in the early 1990s and provides a telephone help line for users and carers, independent advocacy, representation and consultation, a volunteer program, training for other organisations and an online forum. Financial independence is seen as essential and so it is not reliant on the treatment sector for funding but is commissioned by the Drug Action Team to provide specific services. Today they have three offices and three full-time employees. They have also been involved in the national user movement and national policy making. BADSUF receives £112,000 ($AUS194,360) per annum from the Drug Action Team and Supporting People Fund. It also receives money from philanthropic organisations and Drugscope.

- **Reading User Forum (RUF)**, which was formed in 2004 and became a charity in 2005. Reading is a large town located to the west of London. RUF has two full time paid workers supported by volunteers, over 200 members and has free office space in a building with other drug services. The total budget last year was £90-100,000 ($AUS156-174,000) from three local authorities, the Primary Care Trust and donations. RUF provides a mix of peer-led advocacy, support groups, representation and consultation, peer education and harm reduction work. They have recently established the Community Alcohol Support Team (or CAST) to provide a stepping stone into treatment for people with alcohol problems.

- **Cornwall Service User Forum** was established nine years ago. It grew out of a women's treatment group and in response to the difficulties women were experiencing with the treatment system and then expanded to incorporate men. The Forum has supported a network of service users across a rural area with a dispersed population. It has facilitated regular user forums or drop-ins, training for users and service providers, consultations and input into decision-making forums. It was also instrumental in helping to establish another regional forum, the South West User Forum. For five years the Forum was funded to employ a full time coordinator supported by volunteers. Now the coordination role has become voluntary and they receive £15,000 per annum to cover volunteer and other expenses.

- **Kensington and Chelsea Service Users Drug Reference Group (SUDRG)** based in inner London. This began in 2005 when, after attending a Drug Action Team organised service user meeting, two service users decided to try and establish socially based aftercare in the form of a badminton club.

The club highlighted the lack of any out-of-hours services offering support and social activity rather than therapeutic interventions and led to the setting up of a weekend peer-led social club designed and run by service users. By 2007 the club was offering a full weekend service providing drug related information and advice, screening, assessment, referral to structured drug treatment and brief psychosocial interventions supported by 65 volunteers who were both scripted and abstinent service users. It offers a two pronged service – abstinence based aftercare for the volunteers who run the service and want to move on and a Tier 2 service for people with active addictions, many of whom are not engaged with other services. It receives £100,000 ($AUS174,000) per annum which covers wages for two workers and volunteer and service expenses. SUDRG has been instrumental in developing training packages for volunteers offering the key skills required to move into education and employment and is represented in Drug Action Team and commissioning decision making forums.

- **Belfast Service User Forum**, originating in 2002 when there were very few services for injecting drug users and no substitute prescribing, no outreach services and no service user involvement in Northern Ireland. A community worker who was also a closet former drug user decided to address these issues by providing harm reduction and outreach services and a response to anything a service user might present with. Funding was obtained from the Eastern Drug and Alcohol Coordination Team (EDACT) to establish this service in 2003 and the User Forum grew out of it. The Forum now has two workers, operates under the auspices of the EDACT and is involved in lobbying and campaigning work. Recently it has been able to secure £20,000 from the EDACT for user involvement work. They are currently trying to make in roads into statutory services and substitute prescribing to establish service user involvement.

4.4.1 Key characteristics

Typically service user groups are established by a handful of service users disillusioned with the treatment offered to them and many groups are reliant on one or two charismatic individuals. Finding leaders willing to take on this role can depend on luck, particularly in an environment where admitting to drug use is admitting to illegal activity. This means that it can be hard to build service user groups organically from the grass roots.

> *It's all bound up with the prohibition question. If you are an organised and able drug user why on earth are you going to make yourself visible as a person who is stigmatised by putting your hand up as a participant in activities which are illegal and criminalised. So able people often avoid coming forwards for these reasons and people continually struggle about being honest about their lives in those organisations. (Writer and activist).*

As the following histories indicate in some cases the main driver is a wish to make their experiences known to policy makers and planners. In others the motivation is about setting up alternative support services to meet the gaps in the treatment system.

> *We were both heroin addicts. I had done lots of detoxs at home and gone back to it. I went to our local prescribing service and said I need a script and they put me on the waiting list. It was five months until I walked out of the pharmacy with my first dose. The theory behind it was that if people were serious they would wait that long. We discussed it and said this is outrageous so we thought we ought to do something about it. We didn't know anything about user groups or user involvement or the NTA. This was January 2004. Me and my partner decided to run the project together. We were given a folder about user involvement and got some training from the Alliance (see page 71) about advocacy and set up an advocacy service locally. This was all voluntary as we were on the dole. Then we decided to produce a little newsletter with warnings about bad batches of gear to quickly tell active users. We did it at home. The development worker suggested*

we apply for some funding to get desks and printers. We got the funding and now we had a base to work from. We turned our weekly meeting every Monday into a drop-in peer support group for people who didn't get on with the Narcotics Anonymous philosophy but still wanted support to stop using and stay off. (Service user group)

All that was available to me was Alcoholics Anonymous. I went and I didn't like it but there was nowhere else to go and I got into the revolving door of treatment. So I got involved with our regional drug user forum facilitated by the NTA. I was elected vice chair but when I said I was bringing the issues of alcohol misusers to the table I was told this was for illicit drugs only. So I started a support group from my own home and then went asking service providers if I could use their premises. It had to be free of charge because there was no investment in alcohol services. Thankfully a drug and alcohol service let me and we started groups there. I was unemployed and from the building trade and had never done anything like this before. I did it as a volunteer for two and a half years and put my own money into it. I started to get phone calls from service providers saying they had people interested in attending support groups but wouldn't have the confidence to walk in so that's when the one-to-one peer mentoring service started. A lot of our work initially was service user consultations and that's one of the reasons we were commissioned because when we asked what service users wanted, they said more of us! (Service user group)

In 1992 I was in treatment. When I had been there a few months they asked me to become involved in the management committee to provide feedback on the user perspective. To begin with it was just my own opinions. Then I attended a conference and realised they weren't getting a proper representative view so I started up an advocacy group. We met with staff and identified issues in treatment and I got the idea of some kind of organisation that could give feedback on services. By 1997 we had a constitution, chairperson, treasurer, premises and funding from social services. It was all voluntary and no one got paid. We were also running an advocacy service and visiting people in their place of treatment. We got a service level agreement for our services in 1998. We got charitable status in 2000 and funding for a part-time manager and for the advocacy service. I chaired the DAT [Drug Action Team] for two years and line managed the commissioning manager and DAT [Drug Action Team] coordinator. That's a big step for me as a service user. (Service user group)

Initially user groups operate on a voluntary basis. This means that setting up a service user group is not necessarily expensive and can be 'low maintenance' user involvement for providers who only have to provide a room, travel expenses, tea and biscuits (Gilliver 2009b). As confidence builds and the group gains credibility they can carve out a role that is valued by providers and those responsible for commissioning services and are then able to attract funding. For some organisations it has been very important to remain independent from treatment services and able to support their own agenda. A small number have achieved this through gaining charitable status.

> *After a couple of years of doing 60 hours a week voluntarily the DAT [Drug Action Team] manager said come and work for us at the DAT. We said no because although we were on the dole we also had absolute autonomy, no one told us what to do. We did know that we were telling the dole we're not fit for work and actually running a project and fundraising thousands. So we said we don't want to work for you but if there is a way you can commission our service we'd like to sign off benefits and do this properly. We sat down with a blank sheet of paper and agreed to do things like the weekly drop-in, the advocacy service, gather the views of users and represent them at meetings, all the things we were doing anyway. They said okay and agreed to pay for it all. (Service user group)*

> *We are a registered charity and this can be a problem in trying to help other groups to the stage of charitable status. A lot have criminal histories so it can be hard to become*

> *a charity. We set up a Board as autonomous as possible and with no one who has anything to do with treatment services because then it's not an independent user group, so no one from the DAT [Drug Action Team] or from the police. We have the lead specialist from our local hospital on blood borne viruses, a local solicitor who deals a lot with drug users and a friendly chemist who distributes methadone. We also have a couple of service users. Workers from treatment services who were ex users wanted to join but they couldn't because they now worked for the service we would be raising issues about. (Service user group)*

However, gaining adequate funding can be a continual struggle and informants described the difficulties in piecing monies together from a variety of funding sources. It meant a heavy reliance on voluntary efforts and the passion and commitment of those running the group:

> *Funding in the user involvement world is a problem and a struggle. Here they put the user involvement in services out to tender and we won it. But the amount of money they paid was so small it was ridiculous. It leaves a gap and we have had to take on work which has kept us away from home. The funding doesn't allow you to concentrate on your own area because we have to go and make money elsewhere. (Service user group)*

As user groups gain credibility with planners, policy makers and providers they are able to strengthen their voice, become influential and impact on service provision. This can be a gradual process.

> *During the first nine months we found out about all the different committees and DATs [Drug Action Teams] locally and about spending the treatment budget and asked if we could sit on them and represent the drug users' voice. They were extremely wary to start with but as they worked with us over the years they've realised we're not about going in there and saying this is wrong, that's wrong, this isn't going to work and not give them any solutions or answers. We go in there and work with them hand in hand to make things better. They weren't sure how we were going to deal with not getting our own way and they were worried we were going to be punching people. This is what we were told later. They also realised that we could be trusted with confidential information and it wouldn't be spread throughout the drug using community by the next day. The police were worried in particular that we would go off and tell users about drug operations they were planning. When they looked at any leaks it always went back to probation. Some groups will go storming in there like a bull in a china shop and not give people a chance and ride rough shod over them. That does not go down well. If you back people into a corner they will dig their heels in. So you need to learn how to play the game, the personalities involved and try to be friendly about things. We very much sat there and listened for the first six months and realised we were entering a whole new world that we didn't really understand. So we would only interject if we felt we were talking about something we knew about. (Service user group)*

> *It was about building up credibility. It's a two-way thing and people had to get to know us and we had to get to know them. When we first got our office we could only use the client toilets not the staff toilets. We had to come into the building as clients and through reception and then into our office. After a period of time we could go to the staff toilet and then we were given pass cards so we were trusted to have access to the whole building. It's down to hard work, being professional in the way we work, being polite, persistent and sticking with it and being able to have an open mind and hear and to look at all sides of things. Some user reps will be effing and blinding and have personal things going on. It's about being able to look at the big picture and how best you can use your knowledge. Most people who have been successful are quite charismatic. If you are going to top meetings and you can't input into the process meaningfully then there is no point being there if you're not actually working as part of that group. (Service user group)*

> *Initially to be accepted I had to be accepted as professional and that I knew what I was talking about. I know my stuff and they recognised that after a couple of years and then they were willing to talk to me. But it was a slow process and it's taken a few years. It's amazing when I think about my journey from being a service user. (Service user group)*

Gaining credibility and becoming established also meant that the successful user groups acquired a role in helping others to set up groups and sustain them as integral parts of local treatment systems. In some cases this involved setting up regional structures and networks to provide support and information sharing between user groups.

Although user groups might gain credibility with the Drug Action Team and those responsible for commissioning services this did not necessarily mean that they were able to influence changes at an individual service level and user groups can often lack the infrastructure, funding, resources or capability to hold providers to account (Fischer et al. 2008). For one user group it had been absolutely essential to acquire leverage to ensure that service user views had an impact on service provision. This had been done by ensuring that service level agreements included user involvement targets against which the performance of services was measured.

> *The commissioners of service are always open to hearing what you have to say and wanting to help you change services and having you on the Board. But 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. A way of dealing with this has been through putting a service user development strategy together with the DAT [Drug Action Team]. This year every single service which has a service level agreement or any contract with the DAT has a set of seven key performance indicators or targets which they have to hit or feed back on every quarter about what they're doing with user involvement. We've never had it as contractual and performance related pay before so hopefully things will change. Everything else is performance related pay so why shouldn't user involvement be as well? One of the KPIs is to ensure that every service user that comes into treatment has as much information as possible about things that can make a difference to them. There is a checklist on all the kinds of information they should be giving out at first assessment. They didn't do that in the past because it wasn't in the contract. We just presumed they would but they didn't. We had to put together a pack on exactly what sort of information a user should be given on entry to treatment and they will be performance managed on how many have received a pack and how many workers have sat down and gone through it. This will make user involvement a lot more robust. (Service user group)*

Informants were asked why they considered their user group had been successful in establishing and sustaining itself and in having an impact on treatment services. They saw the essential components as:

- Being professional, polite, prepared to listen to other points of view, cooperative and committed to working in partnership rather than being adversarial and critical. It is about moving away from an 'us and them' situation.
- Having a 'can do' attitude and solution focused perspective, working hard, being persistent and always trying again. For example when Addaction experimented with a suggestion board people wrote on it using bad language. Instead of taking the board down they replaced it with chalk so any bad language could be rubbed out.
- Starting small and building up slowly. As one informant said 'you can't just throw money at it, it has to evolve'. This means allowing time to prove worth, build confidence and understand the boundaries and limitations.
- Having charismatic individuals who can motivate others and build on their desire to 'put back and help others'.
- Having champions to support and mentor others. This includes the ability to 'recognise what an acorn is' and then allowing it to grow at its own pace.
- Having fun.
- Only taking on issues that are genuinely helpful and supportive to service users

themselves rather than pushing to achieve things that others think are important.
- Effective and appropriate support, training, guidance and mentoring, and a structured framework for acquiring resources, writing business plans and so on.
- Funding to provide a solid base to work from. Having a phone, desk and a computer can provide momentum. The support of the NTA in funding and encouraging user groups was seen as instrumental in promoting the work.
- Promoting an environment where service users are seen as equally important as providers in delivering positive outcomes for service users.
- Involving current users. If only ex users are involved a lot of data and a valuable perspective is lost. People forget what it is like to be a current user very quickly.
- Being able to offer a tangible product which allows the commissioners of services to meet their targets.
- Being able to move away from the criminal justice and community safety agenda. User groups that sit within the Primary Care Trust where the focus is health find it easier than those located in the Drug Action Team or local government where the focus is community safety.

All informants were asked how they envisaged the future of the service user group in their local area. There was a divide between those who wanted to grow and expand and develop user-led services and others who wanted to consolidate the work that they were already doing, ensure that it was sustainable and not lose the 'sharp end' of user involvement work.

> *We did have plans a few years back to take on the world but as time passes I'm not so sure. We could develop into something big but currently I think it would be best to keep it small and relatively easy to manage. We can do all our things very well and want to represent users as best we can. I wouldn't want to spread things too wide and lose focus. They tried to get us to do different things and we said no. We want to do one thing well rather than many things badly. (Service user group)*

> *I would like us to be working seven days a week, with mentors working in GP surgeries and hospitals and us developing a training arm where we could go out and raise awareness. I want to see the group grow and we are in discussions with commissioners around the country. (Service user group)*

> *If we revived the coordinator post and went into charity status then almost you become an agency. Service user groups who have got charity status and become agencies provide a fabulous service but here you need a sharp end. Once you get into the agency stuff it's another service and I would prefer services to do that and for us to keep an eye on it. If you are running a service you are very restricted in what you can say and do. We are free and can say what we like. We do deliver services but in a non-contracted way and it means we can reach out to people who key workers can't. We can respond to need and if there's suddenly a problem we can get down there and do something. We wouldn't be allowed to do that if we were contracted. There is something spontaneous about user involvement. (Service user group)*

Some commentators described a culture in the service user world where as soon as a group becomes successful, others think they have sold out and left the user perspective behind.

4.5 National User-Led Organisations

No national user-led organisation yet exists in the UK although there have been attempts to establish one as a way of developing a national drug user movement. Many informants considered that the absence of such a body had hampered dealings with politicians, health authorities, primary care executives and regional and local Drug Action Teams.

The first attempt to develop a national organisation was in the late 1990s with the establishment of **The National Drug User Development Agency (NDUDA)**. This brought together methadone and cannabis, crack and dance drug user groups as well as ex-users. It had a membership of 45 groups which included many in Scotland and it operated on two fronts – the more radical user rights side with a focus on overturning drug prohibition and the treatment focused side which worked with the NTA to improve treatment services. It aimed to nurture the growing number of service user groups and promote user involvement as well as taking a pro-legalisation stance.

NDUDA was successful in getting funding from the Department of Health (DoH), the NTA and philanthropic sources (Comic Relief). This allowed it to support a paid coordination post and fund small grants to service user groups. It also ran a number of training contracts, and contributed to policy and planning at a national level including giving evidence to select committees. However funders were cautious about supporting an agency which was lobbying against prohibition and funding was short-term and not adequate to fully support the growth of a national organisation. The under-resourcing led to internal divisions and tensions about directions and goals and it was accused of not being representative of the drug using community and of mismanaging funds. By 2004 NDUDA had collapsed.

The **Methadone Alliance** was established in 1998 by a health professional who had acquired an opiate problem. It aimed to bring both service users and professionals together to respond to the ‘postcode lottery’ of treatment and to lobby for an effective research base and best practice in substitute prescribing. Initially it was run by a volunteer team who set up a helpline and advocacy service. This led to acquiring Department of Health and Comic Relief funding and a number of training contracts. In 2002 it rebranded as The Alliance in order to move beyond methadone users and create a wider alliance across the drug using community, focus on the personalisation agenda (see Putting People, Glossary) and on choice in treatment services. The Alliance was successful in gaining money from the Department of Health for a three-year pilot to develop a national advocacy model with a central hub and nine regional advocates supporting local advocacy and user involvement activities across the country. It is now seeking additional funding from the Department of Health to support an expanded training program for user activists through nine regional workshops covering best practice in commissioning.

The Alliance has 11 staff and runs a national helpline, has an online community where issues can be raised, is building local advocacy and undertakes consultancy, policy and media work. It trains service users and providers in user involvement activities, collects feedback and lobbies to promote user involvement. It has representatives on working parties, produces information and hosts conferences. It has now entered into an alliance with charities working in the drug and alcohol sector and the peak body for independent and community sector AOD services in Europe, the European Association for the Treatment of Addiction, to operate a three-year project to improve service quality across the third sector. This will involve consulting about what is required to achieve standards, establishing core values and working to embed the notion that treatment must respond to the needs of individuals in a respectful way.

The **National Users Network (NUN)** is a virtual organisation set up in 2005 with a membership of 108 organisations, service user groups and individuals. The original intention was to establish a drug user union to provide a national voice for drug users, and it did explore the model demonstrated by the Australian Injecting Drug Users League (AIVL)[21]. However internal disagreements about a constitution and aims have meant that it has remained an informal network. The network gives access to a pool of experience, help and information and aims to promote and support user involvement in all aspects of care, treatment and delivery. Although it has been supported by the NTA it does not receive any funding beyond a small donation to establish a website. It is a developing network rather than one that has achieved penetration at a national level.

Other initiatives at a national level include **Black Poppy**, a drug user-run health and lifestyle magazine with information about health, harm reduction, user involvement, drug law and history.

Finally, for the past three years, funding from

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[21] See Glossary

the NTA has supported an annual **'Voices for Choices' conference** for service users. This has become an important focus for the user involvement movement nationally. However despite these developments many commentators consider that user involvement has been at its most tokenistic at a national policy level particularly given the lack of any strong national user organisation to push the user voice.

4.6 The Future of Consumer Engagement

All informants were asked how they saw the future of the user involvement movement in the UK. Most were agreed that there had been an impressive push to develop user involvement through state nurtured activities via the NTA. It was now officially embedded in the treatment system with resources provided to support it and a richness and range of approaches.

> *There has been progress and if you map active user groups currently existing, this would have been unbelievable in 2000. 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. (Service user development manager)*

> *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. Now it's caught on. There is a national user conference each year and it's quite a movement. Services would say they've got user involvement just by having a suggestion box and to them that was enough. Now they are talking about inviting users to team meetings to discuss the service. Services have been changed. (Service user development coordinator)*

> *The NTA not only funded us but made it de rigueur that every DAT [Drug Action Team] has to have service user involvement. They have standardised services and made sure there are standards that people have to follow. That has allowed user involvement to become big in local areas if you've got the right people there. It's now set in stone in Britain that the customer voice is very important. (Service user group)*

However, despite considerable progress, there is still much to be done and user involvement in many areas is described as haphazard, ad hoc and left to develop without a strategic vision (MP Consultancy 2008). As one informant pointed out 'user involvement won't happen unless it's entrenched. It's all about strategy formation'.

> *Nationally it's not very good and user involvement is not the most important thing on the NTA agenda. DATs [Drug Action Teams] don't have a requirement to involve service users and there are only about four where service user involvement has been led by service users. The rest have been contracted out to get a service user coordinator but they don't have the natural empathy. In the south west there are very few DATs [Drug Action Teams] who have service users on their executive boards or commissioning boards where decisions are made about treatment. I am not optimistic about the future on a national scale but very optimistic on a local scale. It needs to be force fed by the government. (Service user group)*

> *There is a long way to go with involvement and I don't think it's being used to its full capacity especially in terms of the new personalisation agenda. That is obviously user involvement in itself with individual care budgets. It seems like it was a buzz word for a good few years and now the buzz is not so buzzy anymore. They might think it's working and that they have user involvement in the drug treatment field but often they don't. (Service user group)*

> *People complain about it because the NTA and the government don't appear to have the degree of commitment they did eight years ago. I think that's a mistake and fails to look at the way things happen. An organisation like the NTA will put something on the agenda in order to ensure that it is embedded in the system and gets continued and they have done that successfully with user involvement. The extent to which it's successful differs from*

> *area to area. Some areas are phenomenally good and others are weak but you will never have an area where it doesn't happen at all. These days people at least feel they have to pay lip service to it and 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. You see the transformation happen and you see them improving the system. (Researcher and activist)*

There was a consensus about a need to move from activism into increased professionalism and better organisation and concerns about whether it was possible to create a united national movement given levels of animosity between drug user and service user activists. The future of the National Users Network for instance and its ability to galvanise a national voice depended on whether it could resolve these internal tensions and access political and financial support. One way of doing this was seen as focusing on an issue which would attract wide ranging support in line with government policy, for instance discriminatory employment practice. This would require lobbying at a national level to ensure that all service level agreements included guidance about the employment practices of agencies. Others saw a way forward as collaboration with the international drug users movement which is currently developing an interface with the United Nations.

> *Either as a grass roots movement or as an assisted movement we are not doing well. The drug user movement should be achieving change through a singularity of purpose and unity. But there is a lack of leadership and no plan or vision which should be a prerequisite for success. We need to gain a consensus and deliver that to the government. So it's about unification and consensus and this is not being pursed at present. (Provider and activist)*

> *User involvement is still heavily dependent on a handful of charismatic individuals and as a consequence is very open to manipulation. It needs to get better with infrastructure and governance, the kind of stuff that makes the world take it seriously. (Researcher and activist)*

A major limiting factor was seen as the paucity of an evidence base for user involvement. The lack of formal research into its effectiveness and impact and ways in which it could be enabled as well as limited documentation about good practice was seen as a significant obstacle and meant that developments and positive outcomes have gone unrecognised (Hunt et al. 2010) and made funders cautious about supporting the work. Some of this could be overcome by targeted research.

> *What would make a difference is making a tangible intervention in a small place which has economic outcomes and monitoring it. The only time people listen is when you can save money or get better value for money and it requires evidence of improved outcomes. It doesn't lend itself to easy research designs and requires collaboration with user groups. Academic journals where this would be published are not high impact journals and bodies are not interested in funding it. (Academic)*

Informants wanted to see a repository of information for user activists with templates for protocols, terms of reference, advice about funding and so on. This would parallel the development of 'technical advice bureaux' in the mental health field. There were hopes that the NUN would be able to develop such a resource on their website.

The future risks to user involvement work were identified as three-fold. Firstly most agreed that continued funding was crucial to consolidating recent achievements and growth in the movement. However this was under threat from the financial crisis facing the NHS and from a lack of priority being given to the work in national policy. The assumption that user involvement systems were now embedded had lessened their priority at a national level. Although the new national drug strategy and the NTA Business Plan acknowledge that users and carers play a vital role and that 'the appropriate involvement of users is fundamental to effective delivery' (Garratt 2007), there are concerns that with the current economic climate, funding user involvement and drug and alcohol treatment generally will have a lower priority than they have done in the recent past. This would decrease NTA pressure to develop user involvement activities to their full potential.

> *If people haven't caught the wave they are going to struggle now. There was plenty of funding and plenty of pressure from the NTA five years ago when user involvement was the flavour of the month and we happened to catch that wave. The groups now are really going to have to be more committed than us to get the support they need and DATs [Drug Action Teams] aren't being pressurised like they were. The people who have already made it like us have their solid foundations and will be all right. But for new up and coming groups things might change. (Service user group)*

> *One of my worries is that people will see it as a luxury and when we face financial constraints in the very near future user involvement will be one of the first things they will cut. By and large most DATs [Drug Action Teams] spend tiny amounts on this area and for many people it's at least as therapeutic as anything else that the treatment system provides and involvement in that process is transforming. So cutting that will hurt people as much as cutting any other part of the treatment system. (Researcher and activist)*

Secondly there were concerns about the move from centralism to localism which could diminish the improvements of the last ten years. The NTA was created because at the time there was no evidence that local agencies – like the Primary Care Trusts and local authorities – would spend on drug treatment unless there was a strong central push to do so. So the establishment of the NTA marked a big push towards centralisation. But as the NTA has pointed out there is tension between centralism and localism.

> *If it was left to the Department of Health to spend on drug treatment services it would not be a priority because substance misuse does not cause enough health harm compared to tobacco, alcohol, mental health, hip replacements and obesity despite the fact that it drives a lot of social harm caused by criminal activity. This means it is risky to rely on normal health systems to spend money and localism can become populism. It is easier to take decisions at the centre to allocate resources to unpopular groups for the benefit of everyone. (NTA manager)*

> *Local decision-making will always prioritise children's health, cancer and heart disease. This is clearly shown in the alcohol field where alcohol treatment services have had to compete with other disease areas and been under-funded as a result. With power being devolved to the regions agencies may well slip back in their user involvement work as there are no threats or levers to ensure it happens.(National user led organisation)*

Thirdly at the time of writing there is the possibility of an imminent change in government. It is difficult to predict what the policy on substance use of any new government will be although it is assumed that there will still be a philosophy about listening to users (Barnes 2008). However there are also fears that a new government could promote an increasingly punitive and stigmatising policy that sees drug use as a crime issue and users as anti-social deviants who should be punished (Ford 2008).

Nevertheless many informants saw the concept of user-led services as the future with peer-led advocacy, support and outreach having an increasingly important role in the system and acquiring a stronger funding base. The independent service user group was particularly valued in leading the way for service user organisation and activity generally which otherwise could run the risk of becoming complacent, absorbed in the mainstream and diverted from following unpopular issues. However service user groups always suffer from an inherent instability due to a reliance upon a brave few. As one informant said:

> *Currently it is hard times but it's often in the worst times that the best grass roots work is done and if things are hard it can be the biggest boost to paradigms. If the solution*

> *is political it may be the boost required to build a mass movement. These are interesting times. (Activist)*
>
> *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 not talking about the lunatics taking over the asylum, 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. (Researcher and activist)*

In summary many commentators considered that user involvement activity was at a significant crossroads. Despite the fact that the top priority for service users is to be valued and listened to, until now, when people commit to treatment it increases their vulnerability and they risk stigma and discrimination. Opportunities for work are rare and often in services for vulnerable adults which will be hit by new vetting and barring procedures with the establishment of the Independent Safeguarding Authority. Identifying as an ex user of either alcohol or illicit drugs prejudices future chances of employment. The concepts of hope and recovery are not prominent in NHS services and most research is based on those who are in the middle of treatment. This gives a very limited perspective about success and the rewards for recovery. What is required is for services to switch to enabling and promoting recovery and growth and not just managing symptoms.

4. Lessons for Australia: key elements for success

- The achievements of user involvement activities have required government nurturing through a central health authority with responsibility for contracted services.
- Once embedded in the treatment system and adequately resourced, user engagement has generated a richness and diversity of approaches.
- In order to avoid ad hoc development nationally, user involvement needs to be embedded in national policy strategy and accompanied by specific guidelines and systematic monitoring.
- Once established, the next goal becomes moving from activism to increased professionalism. This requires a united national movement and a joint vision and strategy between drug user and service user activists.
- Success will require a strong evidence base and documentation of good practice.

5. The Australian Experience

Australia has had a different experience from the UK of consumer engagement in the alcohol and other drug (AOD) field. This section describes the policy framework for consumer participation activity in alcohol and drug treatment services across Australia and in Tasmania and levels of consumer participation in different jurisdictions. It collates interview data on some of the issues that drug user-led organisations have faced in making the consumer voice heard. Lastly it summarises some of the key differences between the UK and Australian environment and what this might mean for developing consumer engagement activities.

5.1 Policy Framework for Consumer Participation

In Australia consumer participation is broadly endorsed by governments and is most developed in the mental health sector (Bryant et al. 2008a). In 2007 the Australian Injecting and Illicit Drug Users League (AIVL)[22] in conjunction with the National Centre in HIV Social Research carried out research to describe the current arrangements for consumer participation across Australia and to determine the extent of support for consumer participation in drug treatment services (AIVL 2008). They found support for consumer participation activity in drug treatment in the National Drug Strategy, in strategies relating to blood borne viruses and in accreditation processes.

The National Drug Strategy (DoHA 2004) has a broad stated commitment to consumer participation through improved access to quality treatment via the involvement of consumers and drug user organisations and a coordinated and integrated approach through a commitment to partnership. However there is no framework or approach to guide implementation and no specific policies or guidelines at a national level to support consumer participation in drug treatment at a state and territory level.

There are a range of national strategies targeting other health issues, and particularly those related to blood borne viruses like HIV/AIDS and hepatitis C, which have played a role in building a consumer response within drug treatment. These have a strategic commitment to the involvement of affected communities and consumers in developing policy responses and shaping the planning and delivery of services at national level. This means that any developments that there have been in the drug treatment area have been largely due to the link between blood borne viruses (BBVs) and injecting drug use.

This approach was established during the HIV/AIDS epidemic in the late 1980s and developed further in Australia than elsewhere. It was based on the principle that no effective policies could be implemented without the direct involvement of at-risk groups to provide input into policy, program development and delivery. This led to supporting active involvement and the development of grass roots organisations managed by affected communities with government funding at both a state and national level. These organisations gained acceptance in a very short period of time (Crofts & Herkt 1993) and gave credence to drug users as viable partners. Indeed they are credited with being a significant factor in Australia's success in preventing the further spread of HIV among the non-gay population and injecting drug users and in keeping prevalence at a low level (AIVL 2008). They engaged in a mix of peer education, health promotion, support, advocacy and needle exchange provision, acquired memberships and engaged in lobbying and campaigning work. There was also the development of a national umbrella organisation, AIVL, which is currently preparing a history of drug user-led organisation in Australia. These organisations are now a focus for the development of consumer participation in the drug treatment sector.

Lastly there are accreditation processes. As AIVL has pointed out they are not consumer participation policy frameworks but in the absence of policies at a national or jurisdictional level they can provide a structural framework to support consumer participation in service delivery. Many AOD services now engage in these processes through a number of different accreditation bodies. However the Quality Improvement Council which oversees accreditation in health and community services recently developed a set of standards for the drug treatment sector – the ATODS Standards Module

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[22] 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.

(Quality Improvement Council 2005) – yet failed to include standards relating to consumer participation.

5.2 Current Levels of Consumer Participation

Although most health services have general consumer participation policies in place the specific needs of drug treatment consumers are not always identified. This means that in most areas across Australia participation remains an ad hoc process. The exception is New South Wales where the Centre for Drug and Alcohol produced a guide to consumer participation in drug and alcohol services (NSW Health 2005). The guide includes the principles to be followed in implementing consumer participation in services and a number of examples of consumer engagement mechanisms and strategies. In addition South Western Sydney Area Health Services has a general framework for consumer participation in health which includes the blood borne viruses field and drug and alcohol treatment users. These are some of the few examples of the development of a framework to support consumer participation in drug treatment settings. Overall, although services may be doing things, they do not necessarily identify these activities as consumer participation making information difficult to gather.

AIVL conducted a survey to measure levels of consumer participation in 22 pharmacotherapy services, 16 residential rehabilitation services, 12 residential detox services and 14 combination services in Western Australia, Victoria and New South Wales. It found that despite a broad endorsement by government, consumer engagement has not been operationalised within service delivery. Many services do operate ‘low level’ consumer participation where they are involved in providing and receiving information from consumers and two-thirds reported undertaking a survey in the previous 12 months to collate consumer views on planning and delivery. This might also entail having feedback sessions or suggestion boxes and supporting consumers to facilitate and run their own groups. But the survey also found a lack of awareness about the meaning and practice of consumer participation in the AOD sector, communication gaps between consumers and providers about consumer participation and a strong belief among providers than consumers are not interested. In particular the survey found that:

- high degree activities – for example involvement in decision making – are uncommon with only 20% of services reporting consumer representatives in decision making committees;
- pharmacotherapy and residential services report similar types and degrees of consumer participation, although in the residential sector there are more consumer councils and forums;
- most services (85%) give a charter of rights to consumers;
- consumers themselves report little knowledge of consumer participation activities or complaints processes; and
- the majority of both consumers and providers were interested in promoting consumer engagement mechanisms.

As some commentators have pointed out (Bryant et al 2008) there is a need to explore how consumer participation might work in practice and how policies can be constructed to ensure the sustainability and efficacy of consumer participation programs in a way that addresses the concerns and anxieties of all stakeholders.

AIVL has now initiated a demonstration project with funding from Department of Health and Ageing (DoHA). It involves working with five services – three pharmacotherapy, one residential rehabilitation and one detoxification service – in Western Australia, New South Wales and Victoria to establish, pilot and evaluate mid to high level consumer participation projects. The projects have been sampled to include a mix of government, non-government, urban and rural agencies. They entail the involvement of consumers in a range of activities including in decision making, staff recruitment, planning and delivery and membership of management committees and are facilitated by small grants of $5,000-$9,000 in each agency. The demonstration project also entails broader policy development work with state and territory forums about consumer participation in treatment to push the agenda with health departments and encourage them to build policy frameworks. The evaluation of the projects is being undertaken by the National Centre in HIV Social Research. It is intended that a workshop will then bring all key stakeholders together to develop a nationally agreed framework for consumer participation in drug treatment agencies. As one Australian service user organisation pointed out:

> *The history of these activities is that everyone talks about how they all failed. You have to have something that works and you have to start off small and have something that doesn't run for ever and a day but ends at a certain time. Then you can say we achieved this and it worked and build on it and evaluate it easily. Then people see it works and that no one has been bruised by it. It's a difficult area because people feel their work is going to be commented on in a negative way. It's about being sensitive to that and to the organisational fear. (Association for Participating Service Users)*

AIVL is also involved in a consumer driven project, Track Marks, led by the National Centre for Epidemiology and Population Health at the Australian National University to document the contribution that drug user organisations and users of illicit drugs have made to drug policy in Australia. The work involves a nationwide consultation process to:

- develop a set of key principles for supporting meaningful engagement with drug user organisations and users in drug policy development;
- development of an online 'Meaningful Engagement Kit' to include the key principles and a checklist for drug user involvement; and
- development of an online interactive timeline and archive to document the history of involvement in Australian drug policy for the AIVL website.

The project will be completed during 2010.

5.3 User Led Organisations

Currently most of the representation in Australia is largely coordinated by drug user organisations within their own localities. These organisations have been growing as service providers and some have lost their user-led status as they have professionalised. However they are still seen as the main focus for hearing the consumer voice in a number of jurisdictions. These organisations are:

ACT – Canberra Alliance for Harm Minimisation and Advocacy (CAHMA). This is funded to provide a treatment support service with information, advocacy, referral and peer support through peer education workers and a treatment support worker. It carries out training and consultancy upon request and has a weekly radio show reporting the latest news about drugs, drug services and drug policy. For many years it operated as a peer based organisation but a crisis caused by management issues meant that its incorporation was revoked in 2006. It was re-established and is now auspiced by a mainstream AOD service and receives grants of up to $320,000 per annum from ACT Health and the Commonwealth Department of Health and Ageing.

New South Wales – New South Wales Users & AIDS Association (NUAA). This is a peer based organisation almost entirely funded by the New South Wales Health Department, providing education, practical support, information and advocacy. It has 14 staff, a website, a quarterly magazine and a bi-monthly newsflash. It has a community mobilisation team doing health promotion work and an education team developing peer education, it provides advice and information to health workers and agencies and supports peer leaders. It is establishing peer support groups in pharmacotherapy clinics and consumer participation in needle and syringe programs. It would like to see the development of benchmarks for the provision of accessible and user friendly services and to develop a policy and procedure manual for NUAA representatives who attend local meetings.

Northern Territory

- the **Network Against Prohibition (NAP)**. This is a broad network of drug users and concerned community members who oppose prohibition and campaign for the reform of drug policy both within the Territory and nationally. It has a particular focus on the needs of indigenous young people.
- the **Territory Users Forum (TUF)**. This is a peer based organisation that lobbies,

advocates and provides services to its members and other drug users in the Territory. It is run by and for illicit drug users and represents their interests.

Queensland – Queensland Injectors Health Network (QuIHN). This is a state wide service delivery organisation formed from three user organisations and funded by the State and Australian governments. It provides information, needle and syringe programs, treatment and support services, education and training, peer based support and support to families. Although QuIHN would not describe themselves as a user organisation they do have consumer representation on the Board and up to 20% of their workforce are peers. They have 48 staff, four offices, student placements and a volunteer program.

South Australia – South Australian Voice for IV Education (SAVIVE). This is a program for injecting drug users within the AIDS Council of South Australia. It is funded by Drug and Alcohol Services with $125,000 per annum and by The Council of Australian Governments with $130,000 per annum. It works to promote better health for users and their families by providing information, support, referral and equipment. The core of the work is peer education and it employs peer educators in some of the needle exchanges in health services. SAVIVE also undertakes advocacy and lobbying, policy development, a clean needle program and health campaigns and produces resources. There is a large volunteer program and the majority of current staff were once volunteers.

Tasmania –The Tasmanian Council on AIDS, Hepatitis and Related Diseases (TasCAHRD). This provides a range of services for people living with HIV/AIDS and/or Hepatitis C and their families and communities, for gay men and for injecting drug users. These services include education and training, health and harm reduction programs, a website and two needle and syringe programs. It also publishes TASTE, the only Tasmanian-based user magazine. It runs a volunteer training program which encourages the involvement of consumers (and others) in a variety of activities and the building up of skills. This might include office work, the preparation of resource materials and working bees for community events. However unlike most other jurisdictions Tasmania has no consumer led advocacy organisation in the alcohol and drug sector.

Victoria

- the **Association for Participating Service Users** (APSU). This is a non-government organisation funded by the Victoria Department of Human Services (DHS) to provide a voice for users of alcohol and drug treatment services state wide. It was established over ten years ago but only acquired recurrent funding in 2006. It is auspiced by the Self-Help and Addiction Resource Centre and has a steering committee consisting of providers and users who input ideas. APSU is unique in Australia is having a broader focus than the injecting drug user and includes people having difficulties with alcohol. With a staff complement of 1.5 positions, annual funding of $137,000 and a membership of about 220 people, it provides individual and systemic advocacy, training and supervision for peer helpers and a quarterly newsletter. A core activity is training, support and debriefing for members who become APSU representatives. It operates an email network for service users in order to keep in touch with what is happening on the ground. APSU also runs a pregnancy and parenting playgroup for women with substance use issues. It is also in the process of writing up a practical manual to assist AOD service providers to increase consumer participation within their organisations. It is anticipated that the manual will include real life examples of consumer participation including using suggestion boxes, representation on committees or in research, self-run groups and other activities. It is intending to finalise the manual during 2010.

- **Harm Reduction Victoria** (previously VIVAIDS). This has a staff of eight and a statewide membership of over 600 current and ex users and supporters. The bulk of its funding comes from the Department of Human Services but also from the Australian Government and the Department of Health. It provides information and peer education about illicit drug use, practical support and advocacy and runs the Pharmacotherapy Medication and Support Service (PAMS) which is a confidential telephone service for users of pharmacotherapy services. It also has a specific program focusing on dance drugs and produces WHACK magazine. Because of the existence of APSU they have not been involved in consumer participation work although they do sit on a number of committees, provide feedback to government and present at conferences to provide the consumer perspective.

Western Australia – Western Australian Substance Users Association (WASUA). This aims to improve the health and social circumstances of illicit users through a mix of training and education, an opioid replacement pharmacotherapy advocacy and complaints service and a health clinic. The core services are needle and syringe programs and only a small part of the service is about alcohol and drug treatment. Half of the funding comes from DoHA and half from Health WA. The organisation now has 15 staff and a website with harm reduction resources. It has input into a number of committees including those addressing opioid replacement and pharmacotherapy, a workforce development body, an injecting drug use committee, an overdose strategy group and a group developing the quality improvement framework within the Drug and Alcohol Office. However this work remains unfunded.

AIVL's survey collated data from an email questionnaire to drug user led organisations about levels of consumer participation in the AOD sector. This found that:

- only two reported any involvement in the development of accreditation standards through the reviewing of initial standards, informal engagement (for example telephone feedback) and committee membership;
- only two reported specific funding to undertake consumer participation activities in drug services. This included Harm Reduction Victoria funded to conduct the Pharmacotherapy, Advocacy, Mediation and Support (or PAMS) service and WASUA funded by the WA Health Department to conduct the Opiod Replacement Pharmacotherpies Advice and Complaints Service; and
- only four reported membership of committees and working group involvement relating to consumer participation, for example on policy or research advisory committees, regulatory reviews or treatment program advisory committees.

Although not specifically funded to do this work most of these organisations do undertake participation activities as part of a broader health promotion remit. Interviews conducted with organisations as part of this research found they shared common difficulties in progressing systemic advocacy work. These included a lack of funding and commitment from government, a punitive culture in drug services and the stereotyping of consumers.

> *In South Australia there are no consumers on boards or committees. Recently they set up a health consumer committee and they asked for a consumer voice from the drug treatment services and we recruited someone for that. I was also involved on a committee about moving some of the drug and alcohol services to one main site. Other than that we've found it very difficult to have consumer involvement. We tried to have some of our peer educators go to services and be a liaison or support person but they're not interested in that. Otherwise there is really no input from consumers into these services. They see us as children, untrustworthy or not really as consumers, it's not our place. It's also about not wanting us to access some of that more confidential information or controversial stuff, not wanting consumers to actually know and to have information at a high level. Adelaide is very small and there's only a very small core group of people that are interested and also have the ability to turn up at meetings. There are a lot of things working against users. Users interested in rights are also getting older and the younger lot don't seem to be as interested perhaps because we have paved the way with information and harm reduction and they've grown up having access to clean injecting equipment so for them it's not such an issue. We find it really difficult to get young people involved. There are more funding constraints. Years ago with our funding we would have been able to do more advocacy.*

> *Now funding is more closely related to harm reduction rather than advocacy for the human rights stuff. We would need additional funding for that. (SAVIVE)*
>
> *The nature of our service means we get hauled into a number of committees and we are looked at as the consumer voice. We don't get any specific funding for that. Most government agencies call for some kind of consumer representation and we are the ones that fit that bill and we happily tick the box for them. There's a lot of lip service paid to it and there's not a lot of consumer involvement at all really. What there is is being driven by the funders to say that you need to have consumer involvement. As far as service provision is concerned I can't recall any consumer involvement in that whatsoever. In pharmacotherapy programs the client is not even believed, they think they're lying. A lot of drug and alcohol users fall into the view that it's all their own fault and what rights have they got? It's this attitude which drives a lot of drug and alcohol agencies. So the treatment program is not really seen as a health program but is more about getting people to obey the rules. (WASUA)*
>
> *Victorian consumers don't understand the words ' consumer participation' and we just don't have that culture in the service sector in Victoria. In detox services people go in and they're not well and the last thing they want is to be asked about that sort of stuff. Because it's not part of an entrenched culture in drug treatment services it's alien to people, they can't see the benefits of it and don't know anybody who's experienced that sort of thing and people aren't encouraged or empowered to become involved. You get the odd client who really wants to play a role and the odd service who really will encourage the odd client. But there's a great reluctance for service providers to involve clients in planning service delivery. It's all about the problems rather than the solutions or benefits. (Harm Reduction Victoria)*

In terms of improving the situation and progressing consumer engagement, interviewees saw the solutions as an investment in training and education for both providers and consumers, developing good working relationships, resourcing and having a national push.

> *We realised that to get people involved in having a say in service delivery they need training and education to do that effectively. It's no good commenting on policy or participating and running an organisation unless you understand how it all works. So we set up some training and we now have a group of people we can put on committees, get people to participate in focus groups and be part of policy development and planning. We support people and brief and debrief them and negotiate with them to make sure they get paid or get some sort of remuneration. We also have to have relationships with services and that can be difficult because they get worried that we are going to be antagonistic. It was hard work getting those channels open and initially we went to meetings uninvited. It's about getting the work known and producing results. Everything is about relationships. There is an assumption that if you've used drugs that suddenly half your brain is gone and it's very difficult to get over that. Consumer participation has become part of the rhetoric and is in government policy. People love it but it needs resourcing and it needs thinking about, about how much it's going to cost, what it entails. If you are going to make it sustainable you need to think about what resources you need and the skills you need. It does need to be pushed nationally but it needs to be done carefully, not just money on the table, put out a tender and see which services apply. (APSU)*
>
> *The funders hold the whip hand. Unless they take the lead, services will just go on as they've always done. You need to actually attach this to funding so that you have to demonstrate a level of consumer participation or you won't get your funding, otherwise it's just not going to happen. (Harm Reduction, Victoria)*

5.4 Tasmania

Although most services in Tasmania would have the basics of a complaints procedure, there is generally very little consumer participation in alcohol and drug services. A study currently being undertaken about the participation of illicit drug users in policy development (Lucas forthcoming) found no meaningful input in Tasmania.

A consumer group promoting the interests of methadone users was established in 1997. It was called the Tasmanian Users' Health and Support League (TUHSL) and was initially auspiced by a non-government drug and alcohol counseling organisation. TUHSL was successful in acquiring $200,000 from the Australian Government to do peer support and community education work for injecting drug users. They also developed a drug user magazine *TASTE*. Difficulties in sustaining the organisation and a lack of resourcing meant that TUHSL's work was eventually integrated with the work of the Tasmanian Council on AIDS, Hepatitis & Related Diseases (TasCAHRD).

There are now a number of recent developments which are promoting the concept of consumer participation within drug and alcohol treatment services in the state and which will mean an increased requirement to develop and report on consumer participation activity. These are:

- Tasmania's five year strategic plan for alcohol, tobacco and other drug services (DHHS 2008) which highlights the lack of any mechanism to involve consumers in the drug and alcohol field in the state and commits to establishing a consumer participation framework during 2010.
- The Quality and Safety Standards Framework for all Department of Health and Human Services (DHHS 2009a) funded organisations which requires consumer participation and the reporting of it. Evidence of compliance against the standards in the Framework requires consumer feedback about levels of satisfaction and examples of consumer involvement in individual and strategic planning.
- The development of a consumer and community engagement strategy across DHHS services and funded organisations (DHHS 2009b).
- A new model of pharmacotherapy which has a complaints process built into it.
- The appointment of two workers within Advocacy Tasmania to develop consumer and carer advocacy and engagement in drug and alcohol treatment across the State over a 12 month period. It is anticipated that the project will outline a broad consumer and carer engagement strategy on the basis of the advocacy, with a staged approach over three to four years ranging from clients participating in their individual treatment through to input into policy. It is intended that the advocacy work will begin to build the confidence of consumers and their ability to participate.

TasCAHRD has been progressing consumer participation activities. It engages consumers through its front line work and involves them in program development and planning. Its role in working longer term with some consumers means that it is able to build up relationships which can be used to encourage participation. This has taken a number of forms which include:

- having consumer representatives attending quarterly program advisory group meetings and some involvement on the Board of Management;
- consumer participation in focus groups to develop information resources including providing input on design, wording and content;
- using volunteers in an office training program and in the needle and syringe programs to undertake brief interventions with injecting drug users; there are currently about 10 volunteers involved across the organisation; and
- appointing people who are injecting drug users as AIVL delegates to participate in national policy debate.

However TasCAHRD is not a consumer based organisation and there is no ongoing consumer presence to push the agenda for participation across the state. There is also little money to support the work. Although TasCAHRD has tried to squeeze funding from small project budgets to reimburse participating consumers the lack of any specific budget has been a limitation and involving consumers is not considered by funders to be part of core business.

There are a number of barriers to promoting consumer engagement in Tasmania. Firstly

Tasmania has suffered from a culture of denial about the extent of drug related harm and from a failure to commit resources in this area. Secondly elsewhere the push to get consumers involved has come from injecting drug users and in particular from those using heroin who often face the worst stigma and discrimination. In Tasmania there is little heroin or crack use and less than 1% of Tasmanians report opioid use. This means potential difficulties and concerns about adopting models of consumer engagement developed with injecting drug users in other jurisdictions. Lastly the community in Tasmania is small so that issues of privacy and confidentiality present a real barrier to participation. People are often reluctant to identify, especially given the high levels of stigma and discrimination, particularly for illicit drug users. This makes it very different to the situation in large urban centres like Melbourne or Sydney and problematic to encourage involvement and particularly to establish a drug user led organisation in the State.

What this means is that consumer participation activity in Tasmanian alcohol and drug services is starting from scratch or 'ground zero' as one commentator described with no user-led organisation and only a very recent injection of government funding to explore what models might be appropriate.

5.5 In Summary - Comparisons with the UK

What are the similarities and differences in policy and service environments between Australia and the UK which are relevant in thinking about the development of consumer engagement? Commentators who have had input into this research have suggested that the following need to be factored in:

Where the UK is in advance of Australia:

- The UK has better workforce development, higher levels of training for staff and a bigger role for GPs and primary health care staff in tackling alcohol and other drug problems.

- Consumer participation in alcohol and drug services has been institutionalised in policy and practice in the UK but there is no equal level of formalisation in Australia (Bryant et al. 2008b).

- The Recovery Movement in the UK is becoming a key driver for the transformation of substance use services and for working alongside service users as experts in their own needs rather than dealing with them as passive recipients of care. This fuels consumer engagement activity. Thinking about recovery and its implications is less well developed in Australia.

- The UK has a better treatment mix than Australia which makes it easier to tailor services to individual needs. Having choices about treatment makes individuals more willing to engage and makes for more meaningful participation.

- England has completed a national drug service user satisfaction survey, something not attempted in Australia.

Where Australia has some advantages:

- Unlike the UK Australia early on developed a network of funded drug user organisations which potentially provide a framework on which to build consumer participation. However across jurisdictions this network has not been exploited in order to promote engagement activities in drug treatment services. It has however spawned a strong national organisation, AIVL, which can promote the views of drug users. This is lacking in the UK.

- Both countries have a treatment system which has been led by the criminal justice agenda and where alcohol treatment has, until recently, been marginalised and under-funded. However, whereas in England alcohol is not classed as a drug, in Australia there is a more integrated approach to drug and alcohol issues.

Where Australia is just different

- The drug and alcohol market is different. In the UK drugs are cheaper, better quality and easier to get. Interestingly cannabis is not recognised as a problem in the same way as in Australia where cannabis users form one of the biggest groups in treatment. Alcohol is cheaper in the UK but Australia is seen as leading the way in terms of the responsible serving of alcohol and drink/drive laws.

All these factors need to be taken into account when thinking about using UK experiences to progress consumer engagement activity in Australia.

6. Conclusions and Recommendations

6.1 Conclusions

The starting point for those pursuing the goal of effective consumer engagement in alcohol and drug treatment services is to ask a number of questions. These include what does effective consumer participation look like and what is the best way to begin? How can organisations and decision-making bodies be facilitated to accept it and how should they be supported in doing so? What are the best models and mechanisms to use and how should they be adapted for rural, remote and dispersed communities? Overall how will consumer engagement become a priority when, in Australia, it is still a side issue in the alcohol and other drug sector?

This research has explored the implementation of consumer engagement activities at a local, regional and national level in the UK and the impact of government commitment and resourcing. It has focused on implementation issues and how in practical terms to actually get consumer participation initiatives off the ground by examining the experiences of others. It is not a simple process to draw out the lessons that this might offer for developments in Australia and in particular for Tasmania because the policy contexts and service environments differ in significant ways. However it is important to learn from successes and failures elsewhere and there are a number of key messages which can be taken from the UK experience about getting consumer engagement activities established at a front line and operational level through to policy and planning and creating national representative structures.

The key messages are about the critical elements of best practice models, the importance of a strategic approach and how to lay the foundations of effective consumer engagement through promoting cultural change, providing support, empowering consumers and dealing with diversity.

6.1.1 Best Practice Models

The research clearly demonstrates that there is no single best practice model and establishing any kind of typology is difficult as models are blurred and overlap and employ a range of methods and mechanisms. Any approach is therefore about adapting models for particular client groups and treatment environments and being able to offer choice in involvement opportunities. The research explored the use of consultation and representation mechanisms, peer research and the involvement of consumers in producing information and resources, monitoring and inspecting services, training and educating providers and service users, staff recruitment, volunteer work and employment and providing user-led services. Criteria developed for assessing models in the alcohol sector (Alcohol Concern 2007) are useful for evaluating how effective any model is. These include how close consumers are to real decision making, how far activities are actually led by users, what changes they have resulted in, how they connect with the population of service users and potential service users, what training and support is offered and whether they are sustainable.

Implementing consumer engagement is also an evolutionary process. The UK experience demonstrates how models evolve over time and are works in progress which continue to face and overcome strategic and operational barriers. However in the UK now, whenever there is a policy debate, the views of service users are given serious consideration.

In thinking about various models there are some core elements which the research has highlighted. These are that:

- Consumer engagement is about the spirit in which it is implemented rather than the model itself. It requires a genuine commitment from services to make fundamental changes in the way they operate.
- Any representative structure is best placed in an organisation or environment which is independent of the treatment sector.
- There is clarity about the status and authority of the user and clarity about how people are selected to take part.
- It requires a period of acceptance and development and good working relationships.
- Current consumers must be involved, not just former service users.
- It needs to formally and systematically incorporate pathways to employment, training and development for individuals which enables them to move on. It should be

about transforming lives rather than creating professional service users. If consumer engagement is only seen as about improving the quality of services big opportunities are missed in terms of personal and skill development.
- Listening is not enough. A demonstration of the changes made because of involvement activity is also required.
- Consumer engagement activities must be made sustainable whilst also making it a requirement that people move on. It is suggested that 12 to 18 months are ideal periods for people to be involved in participation mechanisms. There is often reliance on a small core of active individuals who burn out. Addressing this requires a community development approach to ensure the continual recruitment of new consumers. This is long-term work.

6.1.2 A Strategic Approach

The experience in the UK shows the value of a strategic approach. There service user involvement is a statutory requirement and has been pushed through the NTA with policies and guidelines. This has meant that every drug treatment service now has an engagement policy and most areas have service users involved in treatment plans and commissioning who are resourced and supported. Involvement is firmly established in the drug treatment system as standard and essential. The impact of the NTA commitment in promoting user involvement activity is partially demonstrated by slower developments in areas like Northern Ireland and Wales where the NTA does not have a remit and by under-development in the alcohol sector where there has been no body to champion it. This suggests that strategy formation is key and must be made mandatory by government.

This approach has been reinforced through standards and accreditation and regulatory and review processes. A key element has been ensuring that the requirement to involve consumers is integrated into service contracts and tendering processes so that it is promoted by funders. NTA criteria for involvement require service level agreements to ask services to display a service users' charter, include users in reviews and promote their access to advocacy.

Lessons drawn from other fields where user involvement is widely practised – for example HIV/AIDS and mental health – demonstrate that strategic planning is crucial in providing a research based tool that clarifies the problem, sets goals and objectives, identifies key players and determines how to engage them in change. It also helps in moving from ad hoc interventions to long term tasks (JRF 2009). Some of the models described here, for example in Croydon (see page 53), show how important structure is to effective involvement even though best practice might be considered to be organic.

However the failure of the NTA to issue specific guidance about how to do service user involvement or any baseline standards about how to embed it in services, combined with a failure to monitor implementation systematically or have a review process with teeth has had consequences for practical implementation. It has meant that there is a lack of consistency across the country and in some cases it is tokenistic with few service users on Drug Action Team, commissioning or executive boards where real decisions are made about treatment. There is no tool kit to guide implementation, local areas are not necessarily pulled up for not doing it and whether organisations are reaching quality standards in this area is determined by self reporting. This means it can be described as alive and well without this being a reality. The lack of prescriptive guidelines is especially apparent in setting minimum standards for support structures – for example around supervision and reimbursement for consumer representatives or the requirement to have dedicated involvement posts in each Drug Action Team. It is also apparent in a common failure to integrate involvement activities into planning, commissioning and service development and to link them to other strategic objectives. This means that user involvement is not seen as a core component of all service delivery activity and can just become extra work where providers are tempted to rely on ready-made groups of service users rather then embedding involvement in their own service delivery.

There are of course questions about how prescriptive to get in order to achieve the desired outcomes and concerns that if any process becomes too prescriptive or is too linked to funding and targets it stifles creativity. For instance some Drug Action Teams, under pressure to show evidence of user involvement in planning and commissioning, have parachuted service users onto committees without thinking about their support needs or establishing frameworks to facilitate consultation with other service users in local agencies. Research undertake by Patterson et al. reinforces the need for guidance which can enable the development of frameworks that are sufficiently flexible to allow for local variations in service configurations and allow local ownership (Patterson et al. 2008). What is required is user involvement targets or key performance indicators in service level agreements against which performance is measured on a regular basis, for example on the kind of information consumers should receive on their first assessment.

In the UK the move to centralism through the establishment of the NTA was a big driver for user involvement in drug treatment. In Australia service development is being driven at a state and territory level and drug treatment is primarily the responsibility of state governments. However AIVL have seen a national approach as critical in order to implement consumer engagement activity and to achieve consistency and compliance. They would like to see the formalisation of consumer engagement through quality assurance standards and through policy set nationally with clear implementation guidelines so that each state and territory has to operate in compliance. This requires moving beyond broad statements of support to concrete, measurable and achievable outcome indicators similar to those in the national mental health plan and national disability service standards.

6.1.3 Cultural Change

Staff attitudes are considered to be a key determinant for effective user involvement and the development of enabling attitudes requires challenging the stereotypes held by providers, the impact of stigma, the social status of drug and alcohol users and the social exclusion they experience. It requires an open organisational culture where the user experience is recognised as valuable and a recognition that language is very important in determining and moulding provider views. Some organisations now see involvement as a discipline in its own right like multidisciplinary working or nursing. This moves it away from being an add-on to becoming an integrated service driven process.

However if one of the criteria for effective user involvement is how far users are involved in real decision making then examples from different models show what a long process it can be, for example, to get service users admitted to team meetings to discuss service delivery issues. A key issue for providers is whether they are willing to 'let go' and involve service users in meaningful ways. Education and training for providers and the demonstration of good practice are vital.

6.1.4 Providing Support

As well as a structured framework within which to engage, the research shows the importance of providing appropriate support. This takes many forms and includes:

- Dedicated additional funding, including resourcing to work in rural and remote areas and to ensure payment for time and expertise of service users.
- Raising awareness to promote staff ownership – it is problematic to consult about user involvement unless there is already a basic awareness of what it is and a structure to support it already in place.
- Leadership by current and ex service users and professional champions;
- Training for both service users and providers which can demonstrate effective models and the benefits.
- An implementation plan which breaks it down into easy steps and which is linked into a strategy and action plan.
- Mentoring and supervision for active consumers.
- Monitoring and evaluation mechanisms to build on experience and good practice and create an evidence base about effectiveness in transforming alcohol and drug strategies and services.
- A respository of information about effective consumer engagement in the ATOD sector – similar to the technical advice bureaux which operate in the mental health sector.

6.1.5 Building a consumer engagement movement

Effective consumer engagement requires having a body of service users who want to be involved. Yet as the research has shown it can be difficult to identify as a user, particularly of illicit drugs, and individuals may also be battling against a distrust of what are often punitive services, literacy issues and low self esteem. Users may not seek out participation opportunities but many want to 'give back' to services and make their views known. A key challenge can therefore be engaging those with a very limited concept of involvement and progressing them from being angry to communicating their views effectively. This can require bonding to a group to build confidence. Descriptions of the experiences of services who have make a full commitment to developing user involvement show that once there is an effective mechanism there can be overwhelming demands to get involved from consumers. For example in both the peer research model in Scotland (see page 51) and in Addaction (see page 58) keeping participation to manageable numbers involved creating a number of ways for people to become involved, for example, by creating peer champions in Addaction services.

The diversity of the substance using population is often seen as a critical obstacle to building consumer engagement activity. There are divisions and tensions between those who use alcohol and those who use illicit drugs, between ethnic groups, different age groups and people from different classes and between current and ex-users. There are also non-service users and those who would not conceptualise themselves as problematic drug or alcohol users. There are splits between those who emphasise harm reduction and those who aim for abstinence and between those whose focus is improving service quality and those who aim for alcohol and drug policy reform. These divisions and splits within treatment populations mean difficulties in sharing the same goals, interests and empathy and they inhibit the growth of a consumer engagement movement.

In the UK much activity to date has been led by users who are white and male. Participants have been self selecting and at the tail end of their involvement with services which can make them unrepresentative of others. Activity has also, as in Australia, often been led by injecting drug users or those substance users who are seen as the most problematic and stigmatised and with a strong identity and culture. The level of stigmatisation and exclusion they face creates bonds between people in a way that may not be true for other problematic substance users, for instance those using cannabis. However it raises questions about how applicable models developed with certain populations might be for other consumers.

Service users themselves considered that whatever models are used, the key to success for user-led engagement activities was about:

- being professional and polite and having a 'can-do' solution-focused attitude rather than being adversarial and critical;
- having respect for consumer expertise;
- starting small and building up gradually;
- having the involvement of charismatic individuals and professional champions;
- having fun;
- having support – the funding to provide a solid base, training to build skills, mentoring and supervision and a structured framework;
- involving current users; and
- offering a tangible product which is of direct relevance to the lives of service users.

6.1.6 Lessons from the Mental Health Sector

In Australia consumer participation is arguably well developed in the mental health sector, although recent research that explored the achievements and struggles of the mental health movement across Australia and in other countries found that, despite policy commitments at both a federal and state and territory level, there is still some way to go in order to achieve a satisfactory level of consumer participation (Hinton 2009). Increasingly the structural or formal arrangements are in place and there are pockets of good practice but the resourcing and support to fully endorse this has not been available which has meant a fragmented and stop-start approach. Tasmania reflects this and falls behind other jurisdictions in both the range and level of consumer activity that it supports. Although the National Standards for Mental Health Services require services to have policies and procedures for participation which are reviewed by external accreditation bodies, there is a lack of mandates on how processes or mechanisms should be facilitated which leaves room for local interpretation and an ad hoc and unsystematic approach. This parallels the history of consumer engagement in the alcohol and drug sector in the UK.

The research concludes that to address this situation requires mechanisms for oversight and for monitoring and evaluation which can build the evidence base (Hinton 2009). The report asks for performance indicators and outcome measures for consumer participation mechanisms in both public and community service organizations (CSOs) and that these be built into contractual requirements for CSOs providing mental health services where the promotion of consumer engagement mechanisms should become a key quality indicator.

6.2 Recommendations

It is recognised that consumers can be significantly affected by the way in which services are delivered and need to be supported to have input into decisions about those services. The challenge is to find a means whereby engaging with consumers becomes the norm and where they can become active participants in policy making and service delivery with real power to influence change. The research suggests that firstly a broad range of approaches with developments building on each other in an evolutionary way is the best way forward. Secondly it suggests that different kinds of consumers, providers and organisations will have their own models of engagement and their own journeys but can usefully build on the experiences of others.

The key foundations for this journey are a structured framework, funding to provide a solid base and building up the capacity of consumers and providers to engage with consumer participation mechanisms and make them work effectively. The following changes are required in order to make consumer engagement in the alcohol and drug sector in Tasmania valued and a standard aspect of quality service provision.

6.2.1 Policy and strategy

The research has demonstrated that strategy which outlines principles and a framework is paramount in building the foundations for consumer engagement and must be promoted by government and reinforced through standards and accreditation, regulatory and review processes. This can then act as a lever for change at the service delivery level. It requires concrete measurable and achievable outcome indicators similar to those in the National Mental Health Plan and the National Disability Service Standards. These need to be embedded at both a national and a state and territory level in order to achieve consistency across the country. Although external pressure to demonstrate consumer participation can led to some tokenistic responses, the UK experience also demonstrates that clear implementation guidelines are required.

Recommendation 1: That the National Drug Strategy incorporate the principles of and outcome indicators for consumer participation.

Recommendation 2: That the principles of and outcome indicators for consumer participation in treatment services be incorporated into the Tasmanian Drug and Alcohol Strategies.

The Tasmanian Quality and Safety Standards Framework (DHHS 2009a) already stipulates requirements for DHHS funded organisations in involving consumers. However these are minimal and seen as a starting point. More detailed requirements should be outlined based on the ATOD consumer engagement strategy currently being developed by Advocacy Tasmania. It is also acknowledged that there is a need for consistency in consumer involvement requirements across all DHHS service agreements. In particular consumer engagement work in the ATOD field needs to be aligned with ongoing consumer participation activity within Mental Health Services whilst acknowledging that the ATOD sector is not currently as advanced in this area and that there may be different issues.

Recommendation 3: That the Australian and Tasmanian 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.

It is suggested that this process should be accompanied by specific guidance and baseline standards to embed consumer participation in treatment and support services so that the existence of consumer engagement mechanisms becomes a key quality indicator for organisations and providers. This may include audits to consider whether any organisational processes help or hinder consumer participation.

Recommendation 4: That the Tasmanian Department of Health and Human Services ensure that any consumer participation framework developed through the Future Directions[23] process include an implementation and action plan, targets, review dates and evaluation processes.

People who use substances can be marginalised and scapegoated. This is accentuated by the illicit nature of much drug use, leads to the negative stereotypes associated with words like 'junkie' and 'addict' and reinforces the social exclusion many substance users face. This exclusion impacts on the quality of their lives, their ability to recover and particularly their chances of participating in the workforce. The research clearly shows how it also impacts on peoples' willingness and ability to get involved in consumer activities.

Recommendation 5: That the Tasmanian Department of Health and Human Services ensures that the portrayal of Tasmanians with substance dependence is underpinned by the principles of respect in all government materials and that the implementation of this is routinely monitored in order to build a consumer culture.

6.2.2 Funding

Beyond short term funding for Advocacy Tasmania to develop an advocacy service and consumer participation framework there is currently no dedicated funding to support the development of consumer engagement in AOD services in Tasmania. A specific budget for activity demonstrates a tangible commitment to consumer participation, makes resourcing available to remunerate consumers for their travel and subsistence expenses and assists in promoting change. Staff time is also essential and specialist posts or designated parts of job specifications focusing on consumer participation can provide an impetus to communicating with consumers. However this is also costly and must be funded.

Recommendation 6: That alcohol and drug service funding bodies include additional funding to support consumer participation initiatives and their evaluation; for example the reimbursement of costs to consumers.

6.2.3 Building capacity

Developing consumer engagement mechanisms in alcohol and drug services requires the establishment of an infrastructure which can build the capacity of both consumers and providers to promote participation. This presents particular challenges in Tasmania where there have been few developments in this area and where there is no independent alcohol or drug consumer organisation or ready made body of consumers willing and able to engage. Neither does Tasmania have any peak representative body for consumers in the health system which, in other jurisdictions, have operated as mechanisms for consumer capacity building. This gap was recognised in a recent review of Tasmanian DHHS-funded peak bodies (Strickland & Goodes 2008) which recommended exploring the establishment of a peak consumer body to represent the voice of consumers of health and human services in a strategic and evidence-based way. However there are currently no external reference points for consumer experiences and expectations of involvement and this may need to be developed. Advocacy Tasmania is a key agency in terms of promoting consumer engagement in AOD services and potentially in providing support and guidance to agencies in

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[23] Future Directions refers to Tasmania's five year strategic plan for alcohol, tobacco and other drug services (DHHS 2008).

establishing effective mechanisms.

Recommendation 7: That the Tasmanian Department of Health and Human Services strengthen consumer engagement with the Tasmania health and human service system by establishing a body to represent consumers and the community, to support engagement activities and to strengthen consumer networks and organisations.

The research demonstrates how awareness raising, education and training for both consumers and providers about involvement activities is seen as a key starting point for building effective consumer engagement. This means that the involvement of consumers should be seen as intrinsic to training initiatives for the AOD and social work workforce and put into practice through using consumer educators. This should include degree and other tertiary education courses as well as ATOD workplace induction processes.

Recommendation 8: That the Tasmanian Department of Health and Human Services invest in supporting treatment services, particularly in the CSO sector, to access appropriate training and skill development around consumer participation activities for providers and consumers.

Recommendation 9: That education and training initiatives for AOD clinicians and service providers include the consumer perspective, information about the value of consumer participation and examples of good practice approaches.

For those recovering from problematic substance use a key motivation can be engaging or re-engaging with the workplace. The research has demonstrated how valuable consumer participation activities and volunteer work can be as pathways towards employment and recovery. This has been developed in the mental health sector where consumer workers are seen as mechanisms for the transformation of services towards a recovery orientation and as vehicles for cultural change and for inspiring hope. This can also be true in the drug and alcohol treatment sector where the experiences consumer workers have had of services and of recovery can promote peer support activities and add a valuable dimension to professional practice.

Recommendation 10: That any consumer participation activity pro-actively considers pathways for consumers into volunteer work and employment

Recommendation 11. That recruitment processes in the AOD sector ensure that the lived experience of substance dependence does not operate as a barrier to employment.

6.2.4 Monitoring and evaluation

The effective implementation of change requires consistent monitoring and evaluation of policies and practices. By frequently asking what works well and why it works well systems of continuous feedback can be developed which enable learning and adaptation to take place. They also allow the development of an evidence base about the role of consumers in changing the way in which treatment and support services are delivered.

Recommendation 12: That consumer engagement activities at State and Federal levels are fully documented, evaluated and publicly disseminated in order to improve the evidence base for consumer participation activity and the sharing of good practice.

It would be valuable to explore possible mechanisms for collating consumer engagement evaluation findings in Tasmania.

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