

PUBLIC DRAFT 2

NATIONAL TREATMENT AGENCY

**A GUIDE TO INVOLVING & EMPOWERING DRUG
USERS**

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A GUIDE TO INVOLVING & EMPOWERING DRUG USERS

i) Forwards

Paul Hayes - Chief Executive National Treatment Agency:

To be added in final document post consultation and peer review.

Bill Nelles - General Secretary for Methadone Alliance

No one would dispute that there have been some changes in the drugs field during the last few years. For drug users, however, the real change has been the increasing emphasis on user involvement in the development and delivery of their treatment services. It is common now to find drug users working alongside drug workers in local and national partnerships to pilot innovation and improve existing services.

This process mirrors changes that are going on in the NHS as a whole. The latest NHS Plan for 2002 states: "Improved patient and public representation and support is at the heart of the drive to build a modern service around the needs of the individual patient".

Drug users in the UK may have been slower to come together in forming groups and organisations than in other countries in Europe, but this has enabled the process to develop with a real understanding of the historical problems involved. Hard work, coupled with real support, has enabled drug user organisations to develop voluntary organisations and charities. They are, in turn, working with the many local groups that are now taking their place as stakeholders in the debate about how to improve our drug treatment.

It is now up to all of us to take this process further. These guidelines distil the experiences of many successful user initiatives, and they are therefore an excellent starting-point to ensure that this happens.

ii) About The Author

Mat Southwell is Chairperson of the National Drug Users Development Agency. He is a member of East London Respect Users Union and National Spokesperson for the Dance Drugs Alliance.

In 1989, Mat was appointed as the Aids/HIV Health Counsellor attached to St Clements Drug Dependency Unit. He went on to found the Healthy Options Team, an award winning, user based harm reduction agency. He became Head of Service and General Manager for East London and City Drug Services, who under his leadership promoted user involvement, employed workers from drug using backgrounds, and supported a number of drug user initiatives. He left the NHS in 1998 and now works as freelance trainer, consultant, and writer.

He is an Executive Member of the UK Harm Reduction Association and on the Editorial Board of the International Journal of Drug Policy.

iii) Definitions

Drug User - Someone with a history of illicit drug taking. This may include both ex and current drug users.

Drug User Activist – A drug user who is actively involved in a drug user group, in advocating for the rights of drug users, or user representation.

User Representative - A drug user activist who has a formal role to represent other drug users on a committee or forum.

A Drug User Self-Organisation (noun) – An organisation run by and for drug users. The term *Drug User Group* is also used at times although this can also relate to more informal social groups of drug users.

Drug User Self-Organisation (verb) – The process of drug users working together in self-organisations or working together to form a self-organisation.

Service User – Someone currently using services or who has had experience of using services. This term may also include potential users of particular service.

User Involvement – The process of engaging drug users or service users in the planning, review or delivery of professional services. As such user involvement is specifically describes the act of professionals engaging drug users in services.

User Consultation – The process of consulting drug users about a local drug service, the range of local services within a particular area, or about national policy initiatives. This may be achieved through formal consultation events, surveys, or partnership working with drug user self-organisations.

Peer Support and Peer Education – These terms are used to describe the engagement of drug users in delivering harm reduction or health promotion initiatives to their peers. Trautmann¹ has suggested a separation between these two terms:

- Peer education is a more passive process in which professionals use drug users to deliver professionally designed health education interventions.
- Peer support is a more pro-active engagement of drug users in working to assess and respond to issues of concern.

Drug User Organising – The overall research term used to describe all forms of engaging drug users, including user involvement, user consultation, peer support and drug user self-organisation.

Drug Users Movement – A general term used to describe all drug user groups and activists without making reference to any specific network or grouping.

¹ Trautmann F (1995) *Peer support as a method of risk reduction in injecting drug user communities* Journal of Drug Issues 25: pg 617-28

Drug Using Community – This term is used to describe the wider population of drug users. Some may feel that the term ‘community’ is misplaced when discussing drug users. However, Warren argues that communities come into being to fulfil specific purposes that individuals cannot satisfy alone². He identifies five core purposes for a community:

- **Production, Distribution & Consumption Need**
Communities provide employment, income and material sustenance to their members.
- **Socialisation Needs**
To teach individuals key values, expectations and behaviours.
- **Social Control**
Regulating behaviour by setting limits, which would be managed in legal communities through coercive measures (e.g. the Police), through remuneration (e.g. through salaries) or through the setting of norms (e.g. group beliefs and values).
- **Social Participation**
Communities provide opportunities for community members to engage with one another.
- **Mutual Aid & Support Need**
The self-help principle between peers within the same community.

It is possible to argue that drug users meet all five of Warren’s core purposes. Seeing drug users as a community offers the positive opportunity to work to strengthen and enhance positive cultural norms and promote collective action.³

Peer Leader – Someone, normally themselves a drug user, with influence and significant access to the drug using community. This person may be a drug user activist or may have built their reputation for more social reasons.

Professionals – Those that work in professional drug services.

² Warren R (1978) *The Community: An introduction to a social system* ed: Houghton Mifflin

³ Friedman S (1993) *Going beyond education to mobilising subcultural change* International Journal of Drug Policy

iv) **Acknowledgements:**

Despite the very limited resources available to drug user self-organisations, England can boast a diverse range of drug user groups. Those that have pioneered drug user organising deserve credit for their persistence, commitment, and courage. The fact that there are too many activists to name check is a sign of the growing breadth and vibrancy of the drug users movement. Particular mention should be made of the Management Committee of the National Drug Users Development Agency that have worked together to reflected collectively on the our the strengths and have worked together to develop strategies in the face of the opportunities and threats faced the drug users movement

Much help and inspiration has been gained from seeing the progress or struggles of sister drug user self-organisations elsewhere in the UK and Channel Islands and around the world.

Recent progress among drug user self-organisations is in no small part due to the specialist funding from Comic Relief through its small grants fund for drug and alcohol self-organisations. Their willingness to also core fund the National Drug Users Development Agency ensured that development support could be provided to local drug user self-organisations while also securing autonomous structures within the drug users movement. Peter Argall, Senior Grants Officer at Comic Relief has been a valued and objective friend through the ups and downs of the last four years of development work. Commissioning an independent evaluation of the small grants programme and the support work of the National Drug Users Development Agency has provided objective information of the value of drug users sharing their own expertise with their peers. Jane McVeigh, CVS (Consultancy to the Voluntary Sector) Consultant has delivered the evaluation in a fair, rigorous, and robust manner, thus ensuring its value to drug user self-organisations, to Comic Relief, and other potential funders.

Grant McNally was appointed as the National Development Worker for the National Drug Users Development Agency funded by Comic Relief. He has worked tirelessly to turn the National Drug Users Development Agency from a vision into a reality. His work with the Comic Relief funded drug user self-organisations has highlighted the potential value of providing peer-based community development support. His work has been pivotal in testing the learning that underpins these Guidelines.

User involvement is increasingly being recognised as an essential part of the service spectrum. This is very positive but it should not prevent us from recognising those early adopters who did the groundwork for today's expansion in practice. Two English drug services deserve particular credit for their integration of drug organising:

- Trafford Substance Misuse Services has employed a professional facilitator and sponsored a number of drug user self-organisations. A constructive engagement between the service and its service users has become central to the operation of Trafford Substance Misuse Services. Ian Smith, the User Involvement Worker, and Mike Smith, the Service Manager, both deserve credit for their work.

- The Healthy Options Team (HOT) has long been a pioneer of drug user organising and again has sponsored a number of drug user self-organisations. Credit is due to the service users/members, community students and staff for their commitment even in the face of substantial opposition. Teresa Jankowska, Nicky Bath and Jaye Foster all deserve particular recognition for leading this NHS, community based drugs agency at different points during HOT's decade of operations.

In addition, three professional drugs organisations funded the National Drug Users Development Agency to undertake pilot work in their local areas. These initiatives have provided positive opportunities to test models and approaches within an English context. Particular thanks are due to:

- Shaun Thaxter, Global Marketing Manager from Reckitt Benkuser for his consistent commitment to the principle of involving drug users. This was demonstrated through the commissioning of a research project, which sought to identify the views of heroin users on Buprenorphine and their wider engagement in treatment services. The company also funded a review of user involvement⁴ on behalf of Hull and East Riding Drug Action Team, which led to a funded user involvement worker.
- Nick Casey from Hastings and Rye for his patience in piloting models for starting a drug user group using a 'contrived spontaneity' model (see Section 4.10 'A Brief History Of The Drug User Self-Organisations').
- Joanne Williams from Staffordshire for funding and promoting a course for drug user involvement for professionals. The summary of that course provided an initial chance to write up some of the theoretical frameworks behind this area of work.⁵ Joanne is now Commissioning Manager for Stoke-on-Trent DAT.

DrugScope have demonstrated a strong willingness to engage the drug users movement and to reflect on working practices with a genuine desire to improved access and equity in working with drug user activist and drug user self-organisations.

Finally, thanks go to the National Treatment Agency for quickly making user involvement a priority in its busy workload and for commissioning the National Drug Users Development Agency to write these Guidelines. Both the National Treatment Agency, and the UK Anti-Drugs Co-ordination Unit before it, have played significant roles in raising the professional profile of user involvement and putting it on the policy agenda. It is this context that has created the demand for the production of the Guidelines.

⁴ Southwell M (2000) *Extending the role of drug users – a situation assessment – Hull*. Commissioned by the Professional Advisory Group – Hull and East Riding Drug Action Team.

⁵ Southwell M (2000) *Course Summary – One-day training event on user involvement for Staffordshire* National Drug Users Development Agency

v) **Peer Review And User Consultation**

Grant McNally, Bill Nelles, Peter McDermott, Sally Taylorson and Paul Hayes validated this draft structure of this document.

Thanks to Frank Bond, Grant McNally, Alan Joyce, Nicki Coe, George Ellis, Erin O'Mara, John Southall, Bill Nelles, and Jaye Foster for their help with producing the case studies that offer an important experiential backdrop to this document.

The draft document is being consulted on through the email lists of the National Drug Users Development Agency and of the international drug users movements. It was also circulated to all member drug user self-organisations of the National Drug Users Development Agency for comments.

The document will also be consulted on through two User Consultation Conferences funded by the National Treatment Agency in February 2002.

In addition, to peer review through the drug users movement, a number of professionals also gave their comments on this document

vi) **Technical Help**

Thanks to Miranda Staunton for her patience in typing much of this document and to Mandy Milsom for proof reading.

1. Background

1.1 Policy Context

One of the most significant features of the public sector at the end of the 20th Century has been the substantial impact of the consumer and patient rights movements. Drug user organising can be justified in policy terms on a number of grounds:

- Patients Charter – The increased consumer rights awarded to NHS patients⁶
- The Community Care Act – The increased obligations of local authorities to consult and consider the views of their service users.⁷
- The Advisory Council on the Misuse of Drugs – (ACMD) Promotion of community models as a well evidenced harm reduction strategy.⁸
- The increased focus placed on patient involvement in the new NHS.⁹
- The obligation to consult patients in the planning and provision of health services and over any proposed changes to services.^{10 11}
- The right to comprehensive locally based independent advocacy.¹²

1.2 User Involvement In English Drug Services

Despite this strong policy foundation, it is notable that at the turn of the century little progress had been made in relation to involving drug users in drug services. So significant was this omission that in 1996, the Government's 'Effectiveness Review'¹³ had to remind drug services that the Patients Charter did apply to its service users.

However, recent Government guidance to the drug field, and the linking of new user involvement with new funding, has given an added impetus to this important area of work. At the same time, it is important to note that the UK drugs field has limited expertise in this area. While there is clearly a stronger and growing commitment to involving drug users, it is vital that this interest is matched by an application of best practice. This document is written to support those in services seeking to play a dynamic role in promoting user involvement, encouraging patients' rights, and supporting the development of drug user self-organisations.

Inevitably, in any emerging field, best practice can be challenging to identify. Commentators have highlighted the limited research that has been undertaken in relation to drug user organising¹⁴. However, a body of expertise does exist, as does some level of research. In addition, a range of theoretical constructs are available both specific to drug user organising and more generally from the field of community organising, community development, and community participation.

⁶ Department of Health (1996) *Patients Charter* Department of Health

⁷ Department of Health (1990) *NHS and Community Care Act* London HMSO

⁸ Advisory Council on the Misuse of Drugs (1993) *AIDS and Drug Misuse Update* London: HMSO

⁹ NHS Executive (1999) *Patients and public involvement in the new NHS* NHS Executive

¹⁰ Department of Health (2001) *NHS Plan – Point 10* Department of Health

¹¹ Department of Health (2001) *Your Guide To The NHS* London: Department of Health

¹² Department of Health (2001) *Health and Social Care Act 2001* Department of Health

¹³ Department of Health (1996) *Task force to review the services for drug misusers: report of an Independent Review of Drug Treatment Services in England* London: Department of Health

¹⁴ McDermott P (2002) *Flavour of the month – users in service provision* Druglink Volume 17 Issue 1

The increased professional interest in user involvement is very welcome. However, it is important to sound a cautionary note. The story of HIV-related outreach work from the late 1980's and early 1990's highlights that good intentions do not always lead to best practice. The wide spread funding of outreach workers posts in this period was later identified as leading to badly focused, poorly managed, and highly variable practice in reaching out to hidden populations of drug users¹⁵. The Advisory Council on the Misuse of Drugs highlighted the 'need for consolidation and a reassessment of the objectives, organisation and delivery of outreach interventions' despite recognising examples of innovative policy.¹⁶ This history of this period highlights the danger of failing to properly design, manage and deliver new initiatives, particularly when these draw on expertise that is not part of mainstream practice in drug services.

For some, the new focus on drug user involvement may be seen as a new fad or passing trend that requires a degree of compliance to access funding. However, such a restricted view fails to see the potential opportunities for all parties in promoting a more effective relationship between policy makers, providers, and drug users.

The importance of the consumers of health and social services being more empowered in their relationship with their care providers has been highlighted by a number of recent high profile scandals. These have reinforced the need for better accountability, more openness, and a clear focus on evidence-based practice. Important checks and balances need to exist in the system. These include effective advocacy, clearly defined patients' rights, and an open dialogue between services and their consumers. It is increasingly recognised that it is not appropriate to expect professional services to both represent their own organisational needs as well as those of their consumers.

Finally, it is important to point out that user involvement is by no means an easy option. While in the long term, it can lead to a far more dynamic role for service users, a more traditional engagement may well be less demanding. As Marchant and Farrant point out (in their discussion of detached youth work) 'it is often easier and quicker to take the provider/advocate role and do it for the adolescent rather than the slower and more difficult task of encouraging self-reliance.'¹⁷

¹⁵ Hartnoll R, Rhodes T, Jones S, Holand J and Johnson A (1990) *A survey of HIV outreach in the United Kingdom* Drugs Indicators Project

¹⁶ Advisory Council on the Misuse of Drugs (1993) *Aids and Drug Misuse – Update* London: HMSO

¹⁷ Farrant M and Marchant H (1977) *Choosing objectives: a stage in the detached work process* Youth Aid

1.3 Linking With Illicit Drug User Populations

The HIV epidemic highlighted the urgent need to strengthen information-gathering systems within the illicit drug using community. Neaigus identified the importance of understanding more about how the injecting drug user community functioned, in order to understand the nature of risk and to plan interventions.¹⁸

HIV also reinforced the need to engage at risk populations. It is accepted that only a minority of drug users will be seeking help from services at any one time and the Advisory Council on the Misuse of Drugs urged drug services to ‘maximise contact with drug misusers.’¹⁹ Professional needle exchange has been an important part of this approach. However, Grund highlighted the value of engaging drug user groups in delivering clean injecting equipment to their peers, thereby reaching more of the unreached²⁰. Bath argued how a secondary needle exchange run by a drug user activist might actually reach populations, such as women, who were actively avoiding engagement with formal services²¹.

Given that drug patterns change and evolve in the illicit scene, then effective lines of communication are required if services are to be aware of changing trends and the need for new interventions.

Jersey Respect is a good example of this approach. They worked with services to understand the reason for rising overdose rates within the local drug using community²². This led to direct interventions among drug users and one drug user activist provided sensitivity training as part of a course for local paramedics.

Drug user self-organisations can have specialist insights and expertise that allow them to design and deliver specialist interventions within the illicit drug using community²³ or may be able to respond rapidly to sudden health crises²⁴.

Furthermore, peer leaders (including drug dealers) have been shown to be important referral routes from the illicit community into formal services where a trusting relationship can be established²⁵.

¹⁸ Neaigus A et al (1993) *The relevance of drug injectors’ social and risk networks for understanding and preventing HIV infection* Social Science Medicine Vol 38 No 1

¹⁹ Advisory Council on the Misuse of Drugs (1989) *Aids and Drug Misuse – Part 1* London HMSO

²⁰ Grund JP et al (1992) *Reaching the unreached: Targeting hidden IDU populations with clean needles via known user groups* Journal of Psychoactive Drugs Vol 24 (1)

²¹ Bath N and Andy *From junkies with love – A qualitative evaluation of a peer based needle exchange* Presentation to 9th International Conference on the Reduction of Drug Related Harm

²² Crosby A (1999) *New group aims to help drug users* Jersey Evening Post

²³ Jankowska T et al (1997) *Benefits of heroin chasing campaign as a harm reduction tool* Presentation to the International Conference on the Reduction of Drug Related Harm

²⁴ The Methadone Alliance (2000) *Urgent health alert for injecting drug users from user-led organisations*

²⁵ Platt E *Even drug dealers can show some pity* The Independent Newspaper

It needs to be accepted that the drug using community is both fluid and evolving. In addition, the illicit nature of drugs causes the drug using community to remain closed to outsiders. Drug user self-organisations or drug user activists may act as gateways or gatekeepers into this population or referral points in formal services. This is an important second theme in the wider process of drug user organising.

1.4 User Involvement And The Individual Drug User

While being a drug user activist can be challenging and arduous²⁶, there are also direct benefits for drug users themselves in becoming involved in drug user organising. Self-organisations may support people as they are trying to find stability with their drug taking, offer them purpose and direction their life (if this is missing) and may offer them insight into new conditions such as Hepatitis C. In addition, drug user organising may act more fundamentally to raise the underlying sense of self-esteem and self-efficacy of drug users, which in themselves are important factors in the process change²⁷. Friedman and colleagues have described this last factor as 'redemption through social struggle'²⁸.

1.5 Conclusion

Many fear that drug user organising will lead to increased conflict and confrontation between services and their service users. However, there may be benefits for both parties in a more mature engagement. Of course, to achieve these benefits both drug users and drugs professionals need to be willing to explore, debate, and probably redefine their working relationships. This is part of the journey towards a more open and effective engagement between drug users and their service providers.

1.6 Section Summary

In this section, the policy framework for drug user organising has been identified. The engagement of drug users around services, and the potential to enhance links between services and the illicit drug using community, have both been identified as unique streams of drug user organising. The benefits and challenges of this work have begun to be explored.

²⁶ Efthimiou-Mordaunt A (2002) *Spanner in the works – Obstacles to practical user involvement and pathways around them* Druglink Volume 17 Issue 1

²⁷ Miller W and Rollnick S (1991) *Motivational Interviewing: Preparing people to change behaviour*

²⁸ Friedman S, Southwell M et al (2000) *Harm Reduction: A perspective from the left* International Journal of Drug Policy

2. User Involvement In Services

2.1 Preparation

The vast majority of drug workers express in principle commitment to involve drug users to a greater degree in services. However, the understanding of the purpose, nature or degree of involvement may vary significantly between different workers within the same service and between different services in the same area. What is important is not whether these differences exist but how these differences are managed.

The voices of drug users add to the rich picture that is vital to the review and planning of services. At times these voices may be uncomfortable to hear, particularly for people who invest substantial time, commitment, and energy in seeking to support the needs of drug users. Engaging staff in a process of honest reflection about their fears, anxieties, and aspirations around user involvement is an essential starting point. It can be helpful to provide training for enthusiasts within a particular health district or region to stimulate interest in user involvement. However, it remains important to engage the whole team in discussions prior to implementation. This type of sensitivity training has been seen as an integral to engaging other marginalized groups within society.

It is important that this work is not seen as forcing compliance on to staff but it is about airing and debating genuine differences that might exist within services. Having said this, there remains a duty for managers and senior professionals to acknowledge that user involvement is now part of the landscape of drug services and has an important contribution in the journey to securing best practice.

2.2 Models

There are a number of different mechanisms that have been employed to access the views of service users. Different options will work best in different circumstances or in different agencies. The key remains to open as many lines of communication as possible. This will allow for a range of service user voices to be heard in the day-to-day running, planning and review of services.

Informal Comments

Many agencies will value the informal process of communication between workers and service users within their agencies. Much intelligence is gathered as drug users talk to staff during their visits or engagements with services. The informal nature of this contact can make it difficult to validate information or connect it to team structures. A number of options can help ground informal comments:

- Designated Duty Manager - Many service user comments are lost if they are not picked up immediately at the point of discontent or when someone wants to offer positive feedback. A duty manager, or another senior staff member, can be available to receive informal comments as they arise. This allows the service to quickly address problems, minimises bad feelings, and demonstrates a commitment to engaging service users.

- Informal Comment Forms – these allow workers to seek the service user's permission to document informal comments. These might go into a comments box or be fed back into other team structures.
- Informal Comments Slot - A feedback slot in team meetings can allow workers to report informal comments to the wider team.

Comments Box

Many services have a comments box, which allow services users to make informal comments about the service. These comments will often be made anonymously and this should be taken into account in choosing the location of comments boxes. However, comments boxes typically have a very low uptake in drug services, which may be due to a number of reasons:

- Poor literacy skills among service users
- English being a second language for some service users
- A lack of understanding of the role of comments
- A belief among service users that comments do not lead to change
- Fears about being identified as 'complainer'

Staff should be encouraged to support service users to write down informal gripes or ideas so that these comments can be fed back through the comments box. It is important to remember that comments may be helpful suggestions about the service and its development rather than always being complaints.

For the value of comments boxes to be maximised, they need to be tied back into agency systems. For example, comments could be a standing item on a weekly team meeting and a formal response could be displayed within the agency drop in²⁹ or included in a service newsletter. It is important that the response is seen to positively respond to the issue, or to apologise for problems, rather than becoming defensive.

It is important that drug users' comments are seen by the wider service using population to affect change. When change occurs because of a positive suggestion or informal complaint, then this should be highlighted to service users to reinforce the value of the process.

The role of comments boxes can be further extended by engaging service users in the process of hearing and responding to comments.

Some private sector companies encourage consumer comments by running a monthly prize draw for anyone who has submitted comments.

²⁹ Healthy Options Team (2000) *Operational Policy* East London and City Drug Services

Complaints Procedure and Patients Rights

Most service specifications will include a requirement for a clear complaints procedure. Statutory drug services will often provide this within the wider complaints framework of their parent organisation. While it is acknowledged that many drug users do have comments or concerns about drug services, this rarely translates into formal complaints. This is likely to be due to a number of factors:

- The power imbalance between drug workers and drug users is seen as too daunting for many drug users.
- Many drug users complain in informal ways or go to other agencies to let off steam (especially in relation to drug treatment).
- Many drug users do not complain because they are concerned that such action could detrimentally effect their drug treatment. Despite the limited evidence to support this view in practice, this perception is still a powerful and enduring obstruction to drug users formally complaining about perceived poor service.
- Complaint procedures are often described and experienced as an endurance test.³⁰ Many drug users feel unable, or see little point, in continuing with an approach, which seems to be never ending and highly time consuming.
- Finally, many drug users do not believe that formal complaints will turn out in their favour

Complaints procedures remain an important way in which drug users can assert their rights within services. However, it remains difficult for drug users to defend their rights if these are not clearly identified and displayed within a service. A set of model patient rights developed by the Methadone Alliance is enclosed at the end of this document (see Appendix A). Giving drug users a copy of their rights as they enter a service promotes better accountability, fairness, and encourages people to complain when they perceive that their rights have been breached.

In addition, advice from specialist advocacy services has also been shown to be effective in supporting drug users to see through complaints about services. This might be from a professional advocacy services, such as the local Community Health Council, or from a peer based services, such as the Methadone Alliance. The 'honest broker' role can also be helpful in supporting the search for a fair resolution, which benefits both the service and the service user³¹.

If services wish to improve their rate of complaints, then it may well be beneficial to seek to simplify systems or establish a common complaints procedure across a single Drug Action Team area. It is important that the rights of workers are adequately protected in any system but there has to be a fair balance between workers and service users rights. Complaints procedures need to be accessible if proper checks and balances are to exist within services. This is important given the monopoly status of many drug treatment services.

³⁰ Southwell M (2000) *Course Summary – One-day training event on user involvement for Staffordshire National Drug Users Development Agency*

³¹ Nelles B (2000) *The Methadone Alliance – drug users and professionals working together to improve treatment options for dependent drug users******

Publicising the outcomes of complaints demonstrates that a service is open and willing to reflect on its practice. The private sector sees complaints as part of problem resolution with its customers and this can lead to stronger ties if a positive resolution is found.

Service Review

There may be points in the life of an agency when either external funders, or the management of the service, wish to more formally review progress. Satisfaction surveys are often used as a tool for gathering the views of service users. However, care has to be taken in the design of such surveys, as service users will often express their general commitment to a service being available, when they still have significant specific concerns. Too structured a survey may prevent service users making comments about other areas of the service.

Seeking the help of an external research agency is often valuable. Engaging drug users in the design of the survey itself can increase user involvement and can help test assumptions expressed by user representatives or drug user self-organisations. Surveys have most legitimacy when an independent research assistant undertakes them. Research assistants can help explore the foundation of drug user concerns in an interview and then document these for feedback to the agency.

Another form of service review is to hold open meetings for service users. This allows people to come and talk directly to the agency, its senior management team, or funders about its role, their experience of using the service, and their expectations (See Section 6 – ‘Running Events For Drug Users’).

A final model of engaging service users around the quality and range of services is the use of Citizen’s Juries. Vision 21, a research and consultancy company successfully delivered this model.³² This illustrates another method of engaging the views of a representative group of drug users. This approach requires careful planning, independent management, and adequate funding.

Service Planning

Service Managers, funders and Drug Action Teams also have the function to plan new services or to extend existing services. Engaging potential or existing service users in this developmental process can help avoid later problems or omissions. However, it is important for those leading the service planning process to be clear about the role of user consultation in the developmental cycle. Many are becoming increasingly cynical at the public sector seeking to consult its consumers at the point when decisions have already been made and essentially compliance is being sought. Brager, Specht and Torenzer offer a useful model for assessing the degree of involvement being offered to community members:

³² Danczuk S (2002) *The jury’s out on user consultation* – Druglink Volume 17 Issue 1

Figure A: Consultation To Participation Continuity:

Degree	Participants Action	Illustrative Model
High	<i>Has Control</i>	Community asked to identify problem and make all key decisions. Resources are made available in order to support accomplishment of community's goals.
B	<i>Has Delegated Authority</i>	Problem identified and presented to community. Community asked to make decisions in a plan, which will be accepted.
B	<i>Plans Jointly</i>	Tentative plan presented. Recommendations invited. Changes to plan expected.
U	<i>Advises</i>	Plan presented, questions invited. Modification to plan made only if absolutely necessary.
Y	<i>Is Consulted</i>	Plan promoted. Support rallied to ensure acceptance.
Y	<i>Receives Information</i>	Plan announced, information given, compliance expected.
Low	<i>None</i>	Community told nothing.

Adapted from 'Community Organising' by Brager, Specht and Torenzer (1987) Columbia University Press.

There is no value judgement implied within this model. Different projects will open themselves to different degrees of participation. Offering too higher degree of participation with no real power will actually be experienced as disempowering³³. However, this spectrum does allow for an objective discussion about the potential to engage the views of consumers in the planning process and to decide at which point drug users should be enabled to participate in the consultation process.

Service Delivery

So far we have discussed drug users as recipients of services who can be consulted, encouraged to comment, or even complain. There is also the potential to engage drug users more dynamically in the process of service provision. Such engagement may take place through peer education or peer support initiatives, through volunteer schemes, and also through the direct employment of people who have life experience of drug taking (See Section 5 – 'Employing Workers To Support User Involvement, Peer Support, and Drug User Self-Organisation').

³³ Friends of the Earth *Community Participation*

In the past, this approach has been hampered by a perception that it is not appropriate to employ drug users unless they are two years drug-free.³⁴ New guidance on this subject is currently under development between DrugScope and the National Drug Users Development Agency. It is hoped that this will create a framework within which services can positively seek to engage drug users as volunteers or paid staff with appropriate support and guidance for all parties.

Research Into Unmet Need

One of the dilemmas of working alongside a closed and evolving illicit drug scene is that agencies may only be aware of particular segments of the drug scene. If service user involvement is the only mechanism used to reach out, then it is likely that agencies will continue to extend themselves to meet the needs of the populations they currently serve. Research agencies have successfully benefited from the privileged access of drug users by using peer researchers or Privileged Access Interviewers³⁵.

Partnering a local drug user self-organisation with an independent research agency has been shown to give significant access to non-service using populations. In addition, the endorsement of key peer leaders was seen to encourage drug users to be open with researchers³⁶. The more established, broad based, and significant the drug user self-organisations, the better privileged access it will have into the local drug using community.

There are examples of drug user self-organisations initiating their own research into unmet need (i.e. Brighton User Group).

Contract Review

Commissioners can also involve drug users in the contract review process with services. This might take the form of consulting drug users or their self-organisations in the run up to contract review meeting or involving user representatives in the actual contract review meetings (See Section 3 – ‘User Involvement And Representation In Committees And Professional Forums’).

³⁴ SCODA *Enhancing drug services: a management handbook for quality and effectiveness* (page 36) ISBN 0 948970 16 2

³⁵ Griffiths P et al (1993) *Reaching hidden populations of drug users by privileged access interviewers: methodological and practical issues* National Addictions Unit.

³⁶

2.3 Section Summary

In this section, we have identified that local services can involve service users on a day-to-day basis and this can help with conflict resolution or at least ensure fairness. A statement of patients' rights and effective service user involvement can both act as important checks and balances to services that often hold monopoly positions in the care of drug users.

Further, this section has promoted the benefits of involving drug user at key points in the planning cycle. User consultation can help build the rich picture that underpins service review and planning.

Engaging service users' voices can identify weaknesses in services, uncover evidence of poor practice, or highlight unmet need. When viewed positively this can be seen as an asset to commissioners, services, and the service using population. The challenge for professionals is to think clearly about how they engage drug users and sustain a commitment to hearing views that may be at times difficult or potentially challenging.

3. User Involvement And Representation In Committees And Professional Forums

3.1 Introduction

The drugs field has had limited success in engaging drug users in professional forums and committees. Professionals give a number of reasons for not engaging drug users in this setting:

- Drug users will not be able to understand or keep up with the business.
- Drug users will not be able to operate in a professional manner during the meeting.
- Meetings may contain confidential information about other service users.
- Meetings may contain sensitive information about service development.
- No one drug user can be representative of the needs of all local drug users.
- There is no point in engaging the opinionated minority who want to come to events or are involved in drug user groups.
- Drug users will not understand the limitations of funding, staffing, and resources that hinder the delivery of services.
- Drug use is a disease or condition requiring treatment. User representatives will inevitably have distorted views about services given due to their illness or condition.³⁷
- It is impossible to know which drug user to invite.

Some of these may be genuine issues but they need to be offset against the benefits of involving drug users:

- Services are provided for the benefit of service users. Engaging service users in a steering or management committee demonstrates that an agency is interested in meeting the needs of their consumers.
- Service user views can be helpful in shaping the design, delivery, and marketing of any agency.
- Understanding how drug users might perceive any change in service or local provision can help managers and commissioners achieve change as smoothly and as effectively as possible.
- Drug users are an important group of stakeholders in local drug service provision. Engaging their voices in joint planning forums adds to the rich picture that underpins the planning, review and commissioning of services.
- Representatives on committees or professional forums can act as important information bridges to drug user self-organisations and at times to the local drug using community.
- Drug users can provide important intelligence about changing needs and problems within local communities. This may help focus more formal needs assessment or, at times, even avoid the need for it.
- Engaging drug users in committees and forums begins to break down the strongly held perception among drug users of 'them and us'.

³⁷Southwell M (2002) *The long march to inclusion* – Druglink Volume 17 Issue 1

Developing an open management culture in an agency or professional forum is always challenging. It requires management, or meeting leaders, to be willing to share information with their colleagues in order to facilitate an honest and open dialogue. Other meeting members need to demonstrate trust and integrity in working with this approach and this all takes time to achieve.

Democratic management models have been shown in theory and research to lead to far better outcomes and more effective organisations. More autocratic or closed structures contribute to the sense of alienation and exclusion and often trigger the behaviours among service users most feared by professionals. Also these issues are not unique to just drug users. Lay committee members, community representatives, and people new to an area, may all struggle when joining an established committee or forum. Understanding the jargon, the short hand, and the inter-agency or interpersonal rivalries is often challenging. Those running committees or forums should accurately assess the potential challenges of engaging drug users. However, this needs to be founded on a desire to overcome these problems rather than searching for reasons to exclude drug users.

3.2 Preparing Your Committee Or Professional Forum For User Involvement

There is a danger that poorly planned user representation will be viewed as tokenistic by drug users and may reinforce ambivalent views among professionals. Involving users requires a commitment to address, and at times challenge, underlying concerns of committee or forum members. Again sensitivity training may be helpful as it is unfair for professionals to work through their reservations in the presence of the user representatives themselves.

The mental health sector has demonstrated significant progress in engaging their service users in meetings. Over time, professionals have learnt to see the contribution that these people can make to their work. The first phase will always be the hardest. However, over time, with coaching and guidance to all parties, drug user representatives can become established and valued members of committees or professional forums.

3.3 Codes Of Conduct

It can be helpful to agree a code of conduct for behaviour in a committee or forum. This allows the user representatives to have clear framework within which to operate. However, this code of conduct should apply to all committee or forum members. This will offer security to user representatives who may fear undermining, judgemental, or prejudicial behaviour from professionals.

Committees need to be tolerant of user representatives making mistakes. This is particularly important when people are engaging in such committees or forums for the first time or are moving up to senior level meetings.

Having systems for managing problems allows all players to see the engagement of user representatives as a journey. For example, having formal debriefing meetings with the user representatives avoids the need for user representatives to be challenged in the main meeting.

It is a misnomer to assume that all bad behaviour in meetings will derive from user representatives. A clear code of conduct allows for clarity about the grounds for removing any person from a committee or forum. One individual's failure should not be seen as the end of user representation, in the same way as it would not be seen as the end of representation from a particular agency or professional group.

3.4 Models Of Representation And Accountability

There are a number of different ways in which user representatives can be engaged:

Link To A Drug User Self-Organisation

Where there is a local drug user self-organisation, representation can be sought from this group. This might include a dialogue about representation and feedback. A contract can be negotiated with the drug user self-organisation to provide user representatives. A contract might also involve canvassing views of other users and ensuring feedback through the meetings of the drug user self-organisation, through an open meeting in a local agency, or through a newsletter.

It is important that DATs or services look to resource such processes. A user representative will often be one of the few people not being paid to attend a meeting. Placing wider expectations on user representatives without adequate resourcing is exploitative.

Selection Via Local Services

Local services might be asked to canvass for interested parties among their service users. Many services will have their opinionated service user. Many shy away from inviting these 'atypical' users onto committees. However, these may be the very people who will have the courage and conviction to express opinions in front of professionals and in a formal meeting setting.

This selection process might be a starting point for a service user group and lay the foundations for a stronger base for representation. The opening up of committees and forums to drug users might in itself give purpose to the formation of a service users group. This can help to overcome the perception among many drug users that professionals are not really interested in hearing their views.

Application Process

User representative positions can be opened up to application. Care should be taken in setting the threshold for this process. In local areas in particular, a low threshold will offer the opportunity to engage as many drug users as possible. The National Drug Users Development Agency recommends the following model for managing application process for user representatives:

- **Invite Self-Nominations**

A flyer should be designed which explains the nature of the user representative role, the expectations of the post holder, and degree of commitment expected. It should also be clear about any remuneration, expenses, or training that would be available (i.e. the benefits to the individual drug user).

These flyers should be distributed through professional outlets, such as local specialist drug agencies, pharmacies dispensing substitute prescriptions, and through non-specialist agencies (i.e. youth and community services, homeless agencies, benefits agencies etc). Outreach workers can also distribute flyers to their clients, and flyers could be inserted in pharmacy needle packs.

The flyer can also be distributed through other local outlets, such as 'head shops' (those selling drugs paraphernalia), club venues, or key 'youth pubs' in the local area.

Engaging drug user self-organisations in advertising this initiative can further support this process. They can distribute the flyer through their membership schemes or peer networks. Adverts can also be placed in drug user magazines or newsletters where these exist.

The local press is another potential resource. Engaging drug users is in itself newsworthy. A story in the local paper would act as free advertising.

The regional Big Issue office should also be considered as another avenue for reaching drug users. Big Issue have demonstrated a strong commitment to drugs issues. Research indicates that 40% of Big Issue vendors are drug users³⁸ and some commentators think the real number may be as high as 80%.

Those interested in becoming user representatives should be invited to ring a number to express an interest. It is helpful if the advertised telephone number is staffed during the nomination period, as people may not respond to an answer machine. Care should be taken in seeking written expressions of interest as this raises the threshold of entry.

- Self-Nominations

Once people ring in, they can be given a chance to talk through the role, to understand the expectations, and also the support available. Those still interested should have their details taken and be invited to attend an assessment day. It may be necessary to take a 'care of' address for the homeless or be willing to contact people by mobile phone or text message.

- Assessment Day

Candidates should be invited to an assessment day in groups of about fifteen (this allows for about a one third drop out rate). Guidance on running events for drug users is covered in Section Six 6.

A group assessment model allows the applicants to be assessed on their ability to work in a meeting setting. Each person would be assessed both in terms of the qualities of their answers and in terms of their engagement in the group discussion. This should be made clear at the start of the assessment exercise.

It is advisable to focus the group discussion on questions about representation, committees, working with professionals, and models of feedback rather than about drugs policy. Care needs to be taken to avoid the appearance of selecting 'tame' drug users that agree with local services and will support established policy.

There should be two to three assessors scoring applicants against an agreed person specification. It is often helpful to invite an independent assessor who might come from a drug users self-organisation, an independent community development, or a voluntary sector support organisation. The National Drug Users Development Agency can facilitate access to suitable drug user assessors in your region. Care should be taken in choosing assessors from local drug treatment services, as this may create difficult conditions for those who are service users of that agency.

It is important to remember that you are assessing people's potential to develop into a role.

- Selection

It is worth picking two people to work as a pair on a committee. This will allow people to support each other in the process. Alternatively, a number of people may be chosen to attend range of different committees and forums across the district or local authority. They could work as a group or form the beginnings of a service user group, possibly also engaging the other drug users that had applied to be user representatives.

Variations On Application Process

For senior policy forums, it may be appropriate to undertake one-to-one interviews. This acknowledges that the threshold for this meeting is much higher and therefore the appropriate user representative would be familiar with an interview process. Alternatively, an assessment process might include a mix of group assessment and one-to-one interviews.

3.5 Training And Development For User Representatives

It is helpful to provide basic training for those taking on representative roles. This should be based on an individual needs assessment but might include training on:

- Local service models
- Local joint planning structures
- How services are funded
- Codes of conduct
- Understanding committee papers
- Working to an agenda in meetings and putting items on the agenda
- Active listening
- Assertiveness training

Local voluntary sector resource centres often provide training and support that might be useful for user representatives.

Mentoring user representatives with a sympathetic professional can also be helpful. It is better for this person not to also have a service provision or clinical relationship with the user representative. A mentor might help user representatives prepare for meetings by working through the agenda in advance. They might also debrief user representatives after meetings to support them to review the content of debates, people's conduct in the meeting, and any areas of concern or contention.

The Chairperson of a meeting can also usefully seek to support and reinforce the user representative(s) for their contribution. This is important, as people may initially feel uncertain of their ability in a new role.

It is important to consider how user representatives are engaged as meetings close. Drugs meetings can appear cliquy to outsiders, while in reality workers are just catching time to discuss quick issues or set up meetings. It is important not to undermine the good work in meetings by leaving user representatives standing on their own after the meeting closes.

3.6 Accessibility Of Meetings

In addition to skilling up user representatives, it is also important to look at the working arrangements of the meeting. Meeting may become more accessible if the following strategies are considered:

- A commitment to using plain English in discussions, minutes and papers.
- An agreement to avoid jargon and abbreviations.
- Sending out papers in sufficient time to allow user representatives to discuss these with their mentor, peers or others in the drug users movement.
- A willingness to explain the background to on-going discussions to new committee members.
- Timetabling presentations on changing policy or practice in specialist areas.
- Providing adequate background briefing papers on specialist topics for non-specialists.
- A public recognition that non-specialist views can provide insights for those very close to an issue, which can stimulate informed debate.
- The commitment to bring all information to the table wherever possible.
- Permission for any committee or forum member to ask for clarification if they do not understand a point or issue. This may lead to an immediate explanation, if a decision is to be taken at that meeting or a later personal briefing if it is an on-going issue.

3.7 Confidential Issues

There are times when meetings may need to discuss confidential issues, such as issues relating to service users, personnel issues, or sensitive developmental issues. This can be managed in two different ways:

- The user representative is seen as a full member of the committee/forum and is therefore bound by the same collective responsibility and confidentiality as other committee members.
- The user representative may prefer to stand outside the committee/forum on a particular issue to allow them to sustain an advocacy or campaigning role.

The key with this issue is not the chosen solution but how it is managed and negotiated.

3.8 Case Study - Bournemouth Drug & Alcohol Service User Forum

Bournemouth is probably the area in England with the most integrated level of user representation. The progress in this area is a combination of two factors: the persistence of one a lead drug/alcohol user activist and the willingness of services to engage this person.

The user representative involved described himself as 'always being a challenger'³⁹. He had a background in business and a range of life experiences outside problem drug and alcohol use. He initially approached his local addictions service, asking for the chance to have a say in how services were provided. Initially the service was wary and sceptical, however, over time they explored how this approach might work. The user representative was invited onto the clinical management team, which included senior management, social services, and senior staff from the local healthcare trust.

Initially this meeting was very daunting and the structure of the meeting felt very disempowering. In addition, staff who had previously had clinical relationships with the user representative also sat on this committee and this was uncomfortable. This all led the user representative to feel initially that the commitment to user involvement was tokenistic.

In fact, this reflected that both parties were beginning the journey of user representation. An initial place on a committee was the starting point but what made this venture successful was commitment of the Chairperson to support the user representative. The Chairperson was very patient and understanding and met in advance with the user representative to talk through the agenda. Over time, the user representative became more familiar with the meeting structure. He went on a number of courses including active listening and drugs and alcohol awareness.

As he became more skilled and confident, so the user representative's value was increasingly recognised. He was invited onto other local working groups and committees including the local Drug Reference Group (DRG), the local Drug Action Team (DAT), and the joint commissioning group. The latter two were seen as most relevant to the user representative as the DRG seemed more about services' relations with each other. The user representative also sits on the management group for the local DAT Co-ordinator and is involved in one of the Expert Groups linked to the National Treatment Agency. The role of the DAT Co-ordinator in fostering and supporting user representation was another important contribution to this successful model.

³⁹ Southwell M (2001) *Notes of Interview with Frank Bond, Co-ordinator BADSUF*

The user representative had a wider commitment to user representative and formed BADSUF (Bournemouth Drug and Alcohol Service Users Forum) to encourage other drug and alcohol users to take part in representation and peer-based advocacy. The group has 200 members and produces its own newsletter. About ten to twenty local drug and alcohol users are involved in representation in different committees and working groups. BADSUF's joint drug and alcohol focus, reflects the integrated nature of local services.

3.9 Section Summary

In this section, the challenges and opportunities of engaging drug users in professional forums and committees have been highlighted. Strategies have been suggested to try and manage these issues. Engaging drug users in any meeting is not fundamentally different for engaging any new layperson. With attention and commitment, effective working relationships can be built and secured. User representation can also reinforce links with drug user self-organisations or support the journey towards such groups.

4. Drug User Self-Organisations

Drug user self-organisations may form with a particular purpose in mind while in other cases like-minded drug users come together as part of the process of shared reflection (see Figure B ‘Community Development Cycle – Section 4.9). Over time these activists can find a greater sense of purpose and direction. The types of drug user self-organisations described below highlight the range of functions and roles that such groups can play and their different support needs.

4.1 Self-Help Groups

Definitions

Self-help groups provide a forum for drug users experiencing similar issues to come together to provide mutual support and self-management (i.e. Ladybirds – group in East London for drug using mothers⁴⁰).

Self-help groups can also provide a forum for education and training on specialist issues affecting the target population. They may also provide a platform for longer-term campaigning or advice work on the core focal issue (i.e. Trafford Hep C).

One of the early examples of self-help groups were those developed for people with specific blood borne viruses (e.g. Mainliners in its first incarnation as a national organisation run by and for drug users with HIV/Aids). The other main type of self-help group are those run for people seeking to stabilise their drug use (i.e. Shapers – peer café project in the West Midlands), or groups for people seeking to become or remain drug free (e.g. FIRM – Fun In Recovery Management based in West London, Wentworth House Users Group in Manchester, or Bolton Ex-Users Group).

Support Needs

Agencies often provide a venue (or can support drug users to access an appropriate venue) to run their respective self-help group. They may also provide support with advertising the event through the agency's service users and through other local providers.

Models Of Facilitation

Self-help groups may operate to an established format such as the model provided by Narcotics Anonymous. In such cases, it is helpful to seek developmental support from these organisations (i.e. Twelve Step Fellowship).

Other self-help groups have developed more spontaneously but over time form their own national structures. For example, the UK Assembly on Hepatitis C has been developed as a coalition of local Hepatitis C support groups.

There may also be professional bodies that have specific remit to support the development of local self-help groups (e.g. the British Liver Trust.)

Local services can also provide a support role to self-help groups, particularly where the aim of the self-help group matches closely with the function of the local agency.

⁴⁰ BathN et al

There is however a difference between a self-organisation and a therapeutic group. Having said this, Mainliners originally grew out of the support group for people affected by HIV/Aids at Phoenix House.

National Organisations

- The Twelve Steps Fellowship
- UK Assembly on Hepatitis C
- The British Liver Trust
- National Aids Trust

Case Study – Re-act

Two Hepatitis C support groups existed in London. Mainliners supported the one in the South and the Bleinham Project supported one in the West. Over time the members of these groups looked to secure a greater degree of autonomy and to develop additional functions to enhance their self-help role. Members of both groups came together to form a new Hepatitis C drug user self-organisation.

Re-act was established with a constitution and successfully applied for funds from the Comic Relief's small grants scheme for drug and alcohol self-organisations. Establishing a formal steering committee has allowed group members to have a wider conversation about issues of shared interest beyond offering mutual aid through the two support groups.

Re-act currently has three functions:

- To facilitate the two continuing Hepatitis support groups within the host agencies.
- To provide health education on Hepatitis C
- To campaign for improved services and treatment options for people living with Hepatitis C.

Members of Re-act sit on both the Department of Health and London Hepatitis C Steering Groups.

4.2 Service User Groups

Definitions

Service user groups are usually established alongside a particular agency to promote and develop an active dialogue between an agency and its service users (e.g. Horizon User Group in Southwark and Lambeth and Drug Dependants Anonymous in Northamptonshire). Such groups might provide a forum for service users to work through concerns, comments, and complaints about an agency. They may also act as a standing forum to allow the service to inform and consult its service users about potential changes or developments.

Sometimes service user groups within a district have a remit to relate to a number of local services or Drug Action Teams (e.g. BADSUF - Bournemouth Drug and Alcohol Service Users Forum).

Support Needs

Service user groups will often relate to, and be supported by, a particular service. The service may offer meeting space and access to practical facilities such telephones, computers and a postal service.

If the agency operates a drop in service, then it can be helpful to run the service user group alongside or in the drop in area. This allows service users to engage in a service users forum as they engage in the wider functions of an agency. This approach also serves to raise the profile of the group and supports it through the life of the agency. This approach has been successfully applied with Swansea User Group.

The agency has an important role in advertising the work of the service user group as they have full access to the potential catchment group of this form of drug user group.

There may be local resources such as generic community development agencies, patients' forums or voluntary sector resource centres that can provide support with this work.

Models Of Facilitation

It is often difficult for workers within an agency to facilitate a service user group. As Brager and colleagues note: "Many sponsors would be more likely to support the right of the constituent group if such autonomy did not pose a threat to their own survival and developmental needs"⁴¹. However, establishing a lead contact person from the service provider can help secure effective line of communication with the service user group.

National Organisations

- National Drug Users Development Agency
- Methadone Alliance
- The Patients Association

⁴¹ Brager G, Specht H and Torezyner (1987) *Community Organising* Columbia University Press New York

Case Study - Trafford Service Users Forum

Trafford Service Users Forum was started two years ago. The initial catalyst for the group was the proposed relocation of the local community drug team. The staff in the agency wanted to ensure that drug user voices were heard in the subsequent re-accommodation of the drugs agency. This was particularly important given problems securing capital funding for the agency's new accommodation.

In order to initiate the group, the lead staff member put up adverts inviting service users to attend a meeting to discuss these particular problems. The idea of an on-going service users forum was also raised. The formation of the group was professionally 'contrived'. However, there was a strong commitment from the start to promote a bottom-up model of community development and to encourage self-determination. The staff member's desire was to create the space within which service users could meet and discuss issues, with the relocation of the service being a particular focus. The accommodation problem gave the group a clear purpose and role, which helped group cohesion. This led the group to initially become involved in lobbying key decision makers and funders. There were regular liaison meetings with the lead CDT staff member to keep the service users informed of changes or progress.

Trafford Services Users Forum has 16 core activists, three of whom are elected to sit on local joint planning forums. They have developed a broader service users' remit beyond the initial crisis. They are involved in representation and are now seeking to engage other drug users attending the agency. One of the drug user activists has developed a questionnaire to help the core group understand the needs and aspirations of the wider service using population. The questionnaire have been placed in all client files and will be handed to service users by staff members at their next agency visit. This demonstrates a creative approach to reaching service users through agency channels while retaining self-determination.

4.3 Advocacy Groups

Definition

Advocacy groups are those established to provide peer-based advocacy alongside services. They may be an adjunct to other forms of drug user self-organisations (i.e. ADAPT – 'Addicts Are People Too' – South-East London), or exist mainly to provide an advice and advocacy function (i.e. Methadone Alliance).

Support Needs

Those that provide advocacy roles may need support and training around:

- The structure and organisation of local services
- Best practice in relation to drug treatment or other services for drug users.
- Complaints procedures
- The process of advocacy itself

Again care should be taken in providing this training from within services, which may themselves be the subject of the advocacy work. Specialist training should not be viewed as means of local services imposing their view of drug treatment policy and practice.

Models Of Facilitation

A specialist advocacy for drug users or those in drug treatment could seek support from a generic advocacy service or from an established advocacy groups working in a parallel sectors such as mental health.

The Methadone Alliance has also helped provide training to local drug user groups and activists developing advocacy services that relate to the drug treatment sector.

National Organisations

- Methadone Alliance
- National Drug Users Development Agency
- Patients Association

Case Study -BAM (Basildon Methadone Advocacy)

Basildon Methadone Advocacy (BAM) grew out of the experience of one individual dependent drug user. This person had been on a long-term Methadone maintenance programme and had evidence of good compliance with treatment. For family reasons, this person decided to move to a new area.

He confirmed with the local drug treatment service that Methadone maintenance was available before beginning the process of relocating his family. However, at the point he sought to transfer his treatment, he was advised that the option of Methadone maintenance had now been withdrawn. Instead, he was offered a community detoxification programme. He sought to appeal internally about this decision but without success. In light of this he approached the national drug users movement and was referred to the Methadone Alliance.

He took out a formal complaint to the responsible NHS Trust following advice from the Methadone Alliance. This led to a formal meeting with the Clinical Director of the NHS Trust and the Consultant with responsibility for his care. In this meeting, the drug user and his advocate were able to produce the evidence in support of Methadone maintenance. They were also able to argue the personal benefits of this treatment option on the life of the individual involved. It was agreed to seek a second opinion from a national drug treatment specialist, who endorsed the drug user's need for Methadone maintenance. The service user was put back on their previous treatment regime.

While advocating his own case, the drug user met other service users. Some of these people were also being forcibly withdrawn from Methadone maintenance programmes following the change of clinic policy. He started to work with these people as peer-advocate with support from the Methadone Alliance. These service users also went on to win their cases and returned to their previous treatment regimes. These people became the core group of BAM.

The nature of BAM's relationship with services has since changed. There has been a significant shift in clinic policy and staffing. This has led to a much more positive engagement between BAM and the local treatment service. While people moving into new areas often highlight disparities in treatment practices, they may also have limited links with other local users. This has been a challenge for BAM, particularly once the immediate crises had receded and the motivation of some local users understandably waned. However, the local drug agency is now willing to work with BAM in order to find a new, more collaborative working relationship and the foundations have been laid for a local peer-based advocacy group.

4.4 Peer Support Groups

Definitions

Peer support groups are usually formed to reach out to non-service using populations. As has previously been stated, Trautman has suggested separating peer support from peer education (see Section ii – ‘Definitions’). Only the former can genuinely be identified as a stream of drug user organising. This more participative approach is endorsed by the World Health Organisation, who in a key statement on health promotion asserted ‘‘It is a basic tenet of the health for all philosophy that...health developments in communities are made not only for but with and by the people’⁴².

Peer support may be one of a number of functions provided by a broader drug user self-organisation (i.e. C Alert – Hepatitis C group in Essex) or be the only function of the group (e.g. The Crack Squad – peer support initiative with crack cocaine users in East London). While these groups are often formed with a specific remit, they may go on to form themselves into more freestanding, self-determining self-organisations (i.e. Project Liban, peer based initiative with Somali Kat Chewers in East London which went on to work around other health issues in Somali community⁴³).

Support Needs

Those engaging in peer-support may require training around the specific issue being targeted and also around the process of dissemination (i.e. techniques of outreach, health education, active listening, etc). Drug users may also benefit from reviewing other health promotion resources, particularly those developed by other drug user self-organisations. This may be drawn both from other examples in the UK and the wider international drug users movement. For example, the Junktion Project, the user group in Portsmouth, gained permission to adapt and use resources originally developed by SAVIVE a member of the Australian IV League.

Models Of Facilitation

Peer support involves engaging a group of drug users in a process of needs assessment, problem solving and developing an intervention. Drug workers supporting such initiatives would usefully have access to the target population (i.e. outreach workers), have a specialist skill in the process of peer-based work or social marketing, or have particular expertise in the target problem.

Variation On Theme

A further model is where established drug user self-organisations become secondary peer support groups by supporting sub-sections of the local drug using community to respond to their own self-identified needs. The most formal example of this approach is the Tribes Project run by NUAA (the New South Wales Users & Aids Association), which is part of the Australian IV League. In this initiative drug users were invited to form together to develop peer support initiatives in response to a particular need within a particular community. This led to harm reductions initiatives with drug using bikers, lesbian and gay drug users, and dance drug users. NUAA were able to offer specialist support alongside the funding and publicised the scheme and individual initiatives through its magazine *User’s News*.

⁴² World Health Organisation (1986) *TargetsForAll*

⁴³ Ahmed S (****) ***** East London and City Drug Services

National Organisation

- National Drug Users Development Agency
- National Youth Agency

Case Study – VOID (Voice Of Independent Drug Users)

Case study pending interview ⁴⁴

⁴⁴ Walling A *A descriptive evaluation of the North East Essex Voluntary Outreach Service* Essex Rivers Trust Health Promotion

4.5 Campaigning Groups

Definitions

Campaigning groups are also described as quasi-political groups⁴⁵. These are groups that represent the rights of drug users in a more general form. This might include a range of the functions of other groups described earlier. In addition, these groups will tend to have a wider remit to campaign for the rights of drug users with services, policy makers, and also with the wider community (e.g. Brighton User Group).

Support Needs

Such groups are more likely to be self-determining. They may be part of an evolution of other forms of drug user groups, reflecting the growing cohesion and thus the development of wider aspirations over time. However, these groups can also benefit from practical support in terms of venues, access to equipment, and facilities.

Models Of Facilitation

Campaigning groups are likely to be more stable and have found a more secure structure over time. Therefore, they will either have established relationships with supporting agencies or be able to operate independently. However, professional drug services can offer specialist support around funding, securing charitable status, and other appropriate functions. This leaves control in the hands of the drug users but builds and secures effective working relationships with local professional services.

The Big Issue's regional offices in the Northwest and in Brighton have both provided support this form of drug user organising.

Some campaigning groups may have wider aspirations that do not fit with the direct role of local services. In such cases the best approach for services is to look for areas of overlap where joint working can take place and to acknowledge other areas (i.e. drug law reform) where joint working is not possible or appropriate.

National Organisations

- The National Drug Users Development Agency

Note:

The Development Agency is a charity and can therefore support groups that are either themselves charities or are seeking to achieve charitable goals. Therefore, if drug user groups are seeking wider political goals then this is not something that the National Drug Users Development Agency will be able to support. However, it can advise groups of campaigning organisations such as those involved in the drug law reform or human rights movements.

⁴⁵ Jose B et al (1996) *Collective organisation of injecting drug users and the struggle against AIDS* in AIDS, Drugs and Prevention (eds) Rhodes T and Hartnoll R

Case Study – East London Respect

Drug users in East London had been engaged in a process of community development since 1991 through the Healthy Options Team. Respect Users Union was formed by local drug users with experience of community development in the health and social care settings who wanted to add a campaigning dimension to their work. This is reflected in the group's logo, which includes the phrase 'Campaigning For Drug Users' Rights'.

The choice of the word union was a deliberate recognition of core groups desire to act as 'shop stewards' for the local using community. Respect drew together many senior local peer leaders and this ensured that the group had immediate credibility with its peers. Respect currently has around 200 members with an active core group of about 20 drug user activists.

The core group do not see themselves as the only representatives of local drug users. They seek to exploit their 'privileged access' in order to canvass the views of local users. One example of this approach was a formal consultation exercise with local users after growing complaints about the perceived heavy-handed management of local drugs scenes by the police. This led to a series of formal liaison meetings between drug users and the police and a number of problems were addressed and resolved.

One of the first major campaigns of the group was against an anti-drugs poster was widely displayed across East London. Despite losing a complaint to the Advertising Standards Council, the group received coverage in the local press *FT and created a strong sense of collective empowerment after its public actions against posters that had caused a lot of anger among the local using community.

The group's desire to increase self-respect within the local using community is further illustrated by their production of Respect T-shirts. Members would openly wear the T-shirts questioning the hidden or ashamed status of being a drug user. Some members reported how wearing the T-shirt gave them more confidence to argue for improved drug treatment services. The group has provided formal training to its members in advocacy and runs occasional surgeries for other drug users experiencing problems with services.

While now fully autonomous and freestanding, Respect Users Union has continued to work in partnership with the Healthy Options Team. This has included a number of peer support initiatives, joint initiatives⁴⁶, and on the creation of a memorial tree in a local park for drug users who have died in East London.

The main problem faced by the group is development capacity. A number of its senior members have secured jobs in the professional drugs field and this weakened the leadership of the group. Funding is currently being sought for a peer development work to support the range of drug user self-organisations in East London. The group is now known as East London Respect as two other areas in the UK and Channel

⁴⁶ Bath N (2000) *Too HOT to house? – A partnership between municipal housing and drug user groups to preserve housing tenancies* Presentation to the International Conference on the Reduction of Drug Related Harm

Islands have formed independent groups under the Respect name sharing a common philosophy and approach.

Variations On A Theme

A number of national drug user self-organisations, particularly those representing recreational drug users, may have a much more strongly focussed campaigning role, which operates almost exclusively in the political arena (i.e. the Legalise Cannabis Alliance, the Cannabis Coalition UK, and the Medical Marijuana Co-operative). Other groups may have a dual function. For example, the Dance Drugs Alliance is mainly a campaigning organisation for dance drug users⁴⁷ but also undertakes advocacy work for individual clubbers and free partiers and promotes safer drug use within its peer group⁴⁸.

Finally, drug users may at times work together with drugs professional to campaign on specific issues (i.e. Action on Hepatitis C). These are not drug user self-organisations but they do provide an important bridge between the professional field and the drug users movement.

4.6 Peer Based Service Providers

Definitions

These are drug user self-organisations that provide services to other drug users. These may be funded in a similar ways to other drug agencies but will usually have a different relationship with their service users. Drug users may be services users, members of the organisation., and also work for the drug user self-organisation on either a voluntary or paid basis.

The four main forms of peer-based service providers are:

- **Services For Run By And For Ex-Drug Users** – Many ex-users have a desire to offer something back to other drug users once they move away from problem drug use. This may lead them to be important players in the formation of a new mainstream drug service (i.e. Exeter Drugs Project). This approach does not automatically lead to a drug user self-organisation, as the agency may be established with a broader based Management Committee and staff team. However, other agencies will remain more connected with their user origins and can legitimately claim to be drug user self-organisations (i.e. Off The Hook).

⁴⁷ Daley M (1999) *The ravers are revolting- Drug-takers are demanding a better deal from club owners. Do they deserve it?* Big Issue

⁴⁸ Dance Drugs Alliance (2002) *18 Things you need to know about drugs* Mixmag February 2002 Edition

- Peer-Based Needle Exchanges - The first ever needle exchange was run by Dutch drug users⁴⁹ and this remains the most common form of peer-based service. The Australian IV League's regional groups are primarily based on peer-based needle exchanges. In many other parts of the world, needle exchanges have become a mechanism for legitimising collective action among drug injectors. This is very important in settings where drug users face substantial scapegoating⁵⁰ and more public drug user organising would be very risky for the individuals involved (i.e. Eastern Europe). Given the quick move to professional needle exchanges in the UK, peer based needle exchanges did not become a mainstream part of the British response to HIV/Aids. However, Mainline Northwest in the Moss Side area of Manchester remains an enduring example of a peer-based needle exchange.

⁴⁹ Byrne J (1999) *Done to, done over, doing it for ourselves- The history of the drug users movement* Black Poppy Magazine Issue 3

⁵⁰ Friedman S (1998) *The political economy of drug-user scapegoating and the philosophy and politics of resistance* Drugs Education, Prevention and Policy Vol. 5 No 1

- Peer-Based Outreach Services – There are international examples of outreach being another service provided by drug users to their peers. This may be an adjunct to peer-based needle exchanges (i.e. Australian IV League - AIVL) or it may be the primary function of the group (i.e. Brugerforen – the Danish drug users self-organisation’s work in Copenhagen). The most common form of peer-based outreach service are dance safety initiatives. These may be either overtly or implicitly self-organisations of dance drug users reaching out into the club and free party scene (i.e. Crew 2000 in Edinburgh⁵¹). In some settings, this extends to providing a pill testing service (i.e. France and Germany).
- Peer-Based Community Development Teams – These are agencies providing support to other drug users to engage in drug user organising. These will normally exist as an adjunct to a national network of drug users self-organisations. This is part of the function provided by the National Drug Users Development Agency in the UK and Channel Islands. Similar agencies exist in Australia, France and Holland. Usually, these agencies will also act as the peak organisation for the national network of drug users self-organisations, with a democratic structure linking back to their member organisations.

Support Needs

These organisations will often have significant organisational development needs. As with any other newly formed agency the first phase of development is the most arduous. The real challenge is to be able to offer professional support to these groups without undermining the process of drug user self-organising.

Commissioners often look to bring in a professional parent organisation as a helping hand. In fact, this approach has led a number of innovative drug user self-organisations to be subsumed into mainstream professional services and for the peer-based nature of the agency to be lost. This is not usually deliberate process but it reflects the expertise of professional drug services in running a particular form of drug agency. The standardisation of systems, employment practices, and operational policies leads these peer-based service providers away from their user origins.

Providing organisation development still remains an important issue. Committed drug user activists may have substantial skills in providing services to their peers but may not know how to run an organisation. This experience is best evidenced in the early history of Mainliners, where the user volunteers lost control of their agency after facing a crisis in running the organisation. While Mainliners has gone onto be a valuable professional service, this was the end of its time as a drug user self-organisation.

One model that can be helpful is where commissioners contract with a mainstream drug service to mentor, or even to directly manage the drug user organisation, with an explicit timetable to achieve full self-determination. This model worked successfully when East London and City Drug Services supported Project Liban through its early development phase and is the basis on which Mainliners is offering support to the UK Assembly on Hepatitis C.

⁵¹ McDermott P (1993) *Crew 2000: Peer Coalition in Action*

Variation On A Theme

There is also a hybrid version of a peer-based service provider. These are agencies that operate from a user-based model but whose parent organisation is a mainstream drug service provider. The most notable example of this approach is the Healthy Options Team (HOT) in East London⁵². HOT's staff team is drawn from both drug using⁵³ and non-drug using backgrounds and all working within the framework of a community development model.

The benefits of this approach are that the drug user self-organisation is provided with the support and backing of a more established organisation with expertise in the drugs field. The downside is that these parent organisations will often, over time, water down the staff team, service model, and slowly drain away the agency's community approach until it is fundamentally a mainstream drug services. Another problem arises where the parent organisation is the main service provider in an area. The drug user self-organisation may be drawn into conflict with other agencies in its parent group, or even with its own management, in advocating for, or representing the views of, local drug users. This problem is best illustrated by the experience of ACTIV – the Canberra drug user self-organisation (part of AIVL), which was closed down after a criticising its 'sister organisation' the local drug and alcohol agency. ACTIV was later reconstituted as an independent organisation and the commissioners switched funding away from the professional parent group.

4.7 Defence Groups

Defence Groups are those that develop in response to a local crisis and, as a result, the group is normally formed with a specific purpose and goal.

One of the earliest examples of a drug user group in the UK arose among patients of Dr Anne Daley when she was under investigation by the General Medical Council in 1985.

Patients of Dr John Marks developed a similar campaign when the heroin-prescribing programme in the Wirral was withdrawn in 1995^{54 55}

Established drug user groups may take on temporary defence functions in the face of local crises (e.g. East London Respect's successful 'Who Shot HOT?' campaign initiated after the Healthy Options Team was threatened with closure in 1998 or ADAPT's wider campaign around private prescribing doctors in 2001).

⁵² Burke T (1992) *HOT House* Young People Now Magazine

⁵³ Southwell M (1993) *Have the luatics taken over the asylum? A review of the Healthy Options Team's employment policies* Drug News Magazine

⁵⁴ Ashton M (1995) *Rooftop protest as John Marks loses last clinic* Druglink

⁵⁵ Henman A (1995) *Drogues legales: experiences du Liverpool*. Editions du Lezard

Given the spontaneous and situation specific nature of these groups, it is not possible to give advice about support needs and facilitation. However, such local crises can initiate or invigorate drug user groups as they give a strong focus for work and a clear collective goal. As Queen points out, shared identity will increasingly manifest itself when 'rivalries within (the community) are overshadowed by conflict without.'⁵⁶ The challenge with defence groups is to form a sustainable model of drug user self-organisation, or to tie in those activists mobilised by a specific issue, once the specific crisis is over.

4.8 Drug User Magazines

Definition

These are magazines run by and for drug users. They may include one or more of the following functions:

- Peer-based health education
- Harm reduction
- Supporting advocacy
- Disseminating models of drug user organising
- Acting as a point of shared reflection for the drug using community (see Figure B in 4.10: 'Understanding The Nature And Role Of Drug User Self-Organisations')
- Informing its readership about the local or national debate on drugs policy and practice
- Feeding back from consultation events
- Reporting on local, national, or international conferences
- Discussing the role, effectiveness, and direction of the drug users movement, national networks of drug user self-organisations, or individual drug user groups
- Wider lifestyle issues and community news
- Local information about services

A number of national or local drug user organisations run drug user magazines (i.e. The Users Voice linked to the John Mordant Trust). These provide a key mechanism for reaching beyond those who are actively involved in the day-to-day running of groups. Other magazines will be independent operations that work alongside other drug user self-organisations (i.e. Black Poppy and Monkey).

Some groups run their own newsletters to keep their members informed of progress (i.e. BADSUF newsletter).

Drug user magazines can also be used to disseminate information to a wider constituency thus creating a 'virtual' group among those affected by an issue but not directly attending a self-help group (i.e. Hep Cats – magazine for people with Hepatitis C in Cardiff).

The final form of drug user magazine is one run under the auspices of a professional organisation but with a significant presence of drug users on the editorial group (i.e. Mainliners Newsletter).

⁵⁶ Queen S (1923) *What is 'community'?* Journal of Social Forces pg 381

Support Needs

Drug user magazines have many of the same support needs as other drug user self-organisations. However, they may also have specialist needs around magazine development (i.e. layout, editing, working with printers, and distribution).

There may be sympathetic journalists who might offer specialist support to these groups as successfully happens with the Mainliners Newsletter.

Drug user magazines are increasingly communicating over the Internet within the international drug users movement. This can be valuable in terms of sharing expertise and material.

Models Of Facilitation

Drug user magazines can be challenging to fund and organisationally support. Funders or services may be interested in the health-based elements of a magazine. Users may read the magazine because of its wider reflection of community concerns and views. The dilemma for drug user magazines is that too heavy a focus on health turns off their readership, while continuing to act as an independent voice for drug users may bring them into conflict with those that fund or support them.

A good compromise can be for commissioners to fund the health element of the magazine, acknowledging that the wider content plays an important role in the magazine's credibility in the eyes of its readership. The wider packaging of this health information within lifestyle features and community news is thereby seen as a tool to ensure penetration into peer networks. This arrangement can be publicly declared inside the magazine.

Case Study – Black Poppy

Black Poppy magazine was formed in West London in 1999. Initially it was a local magazine supported with funding from the local Drug Action Team and practical help from a local needle exchange. This initial engagement with services was important in underpinning this first year of work by providing the magazine with access to office space and computer equipment. The magazine quickly established a strong connection with its target audience covering a range of health, social, and life style issues. The core group's confidence grew in their own abilities and they secured team working skills

The Editor also went to the International Conference on the Reduction of Drug Related Harm and was able to share experiences and ideas with those running drug user magazines in other national settings.

After the publication of the first edition, the magazine then started to face problems. Its original backers started to question the content and approach of the magazine. This was in particular because the DAT's police representatives stated that they could not support written material that appeared to endorse illicit drug using. The needle exchange also withdrew its support.

Over the 2000, the magazine had to establish itself as a fully independent venture. The magazine had to relocate into someone's house, equipment had to be purchased, and production, editing and distribution skills had to be secured by the Editorial Team. This was a difficult period in the development of the magazine. For example, one whole edition had to be re-written after it was lost after a computer crash. Trying to develop the magazine under these conditions led to significant problems for the volunteer editorial team. Even though its dissemination through the national drug users movement, had given it a wider national profile and significant acclaim within the drug using community, it was hard to respond to the growing demands and expectations.

However, 2002 sees the Black Poppy team back in the swing of things having benefited from funding from Comic Relief. Plans are in place to expand the funding base of the self-organisation. Circulation has risen from 2,000 in its first year to 4,000 copies. There remains much wider demand for the magazine from both services and drug users, which Black Poppy does not have the resources to meet.

In addition to free distribution on the street and through prescribing pharmacies, 199 drug users are regular subscribers to the magazine and 300 professional organisations buy copies ranging from a couple of copies to the box load. Readers letters and the profile of subscribers highlights how the magazine reaches into areas without drug user groups and creates an engagement with the wider drug users movement for those in more isolated areas. It is important to note the drug user magazines are often read by a number of users. It was estimated that on average four people read every copy of Mainline magazine in Amsterdam.

Black Poppy has a core group of about seven writers with other occasional contributors. Black Poppy's Editor points out that a magazine is a very demanding form of drug user self-organisation, given the pressures of deadlines, the need for clear organisation system, the demands of distribution, and the comparatively high costs of the venture. A major breakthrough has been the recent appointment of a secretary.

4.9 Understanding The Nature And Role Of Drug User Self-Organisations

It is best not to see drug user self-organisations as somehow representative of the entire drug using community in a local area. However, they do provide a valuable point of access into the local drug using community. In this way drug user self-organisations can provide a stable point of contact between services, planners, and the local drug using community.

It should not be forgotten that drug users already operate within local groups. As Grund notes: 'Habitual drug users are often organised in small often dyadic friendship groups. These provide IDUs (injecting drug users) with opportunities for partnerships aimed at producing resources, through various hustles, to buy drugs.'⁵⁷

⁵⁷ Grund JP (1996) *Peer-driven outreach to combat HIV among IDUs: a basic and preliminary results* in AIDS, Drugs and Prevention (eds) Rhodes T and Hartnoll R

Many drug user self-organisations seek to draw these friendship groups into a more cohesive engagement that has a purpose beyond funding, buying, and taking drugs.

Inevitably, a core of activists will maintain any group even where there is a wider membership. Membership of drug user self-organisations is likely to be fluid, with some individuals remaining active members over a period of time, while others will come and go.

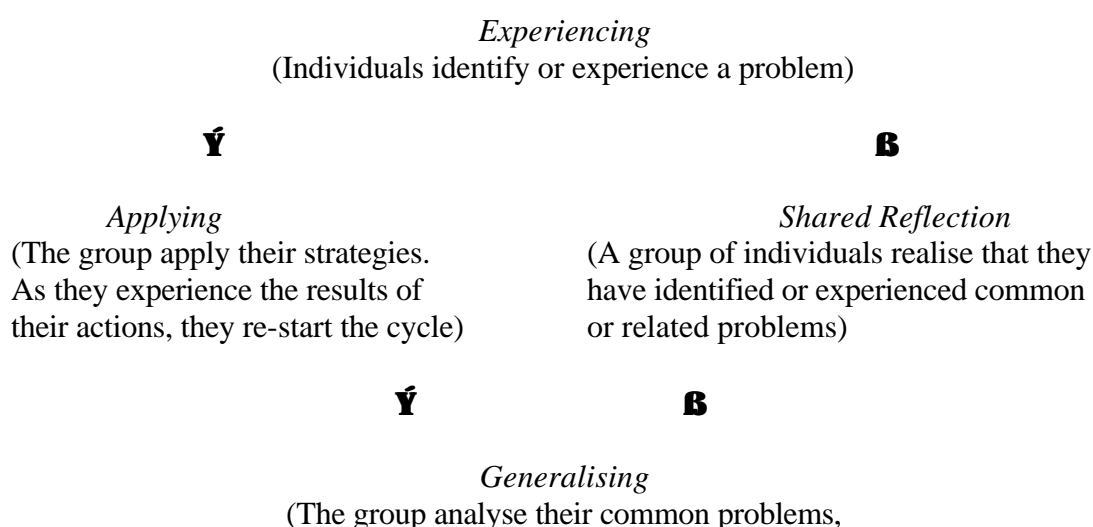
As groups become more established they will sink deeper roots into the local community. As this happens they may be fairly viewed as securing a profile and engagement with their constituency, even if these drug users do not formally become members of the drug user self-organisation.

When groups achieve this degree of development, the analogy of a drug users trade union can be helpful. It highlights how a core group of activists might relate to a wider membership (or constituency) of local drug users. Very few user groups in the UK and Channel Islands have achieved this stage of development at the point of writing, although this process can be evidenced from international examples. Drug user magazines are often an important part of this process as been shown in France, Germany, and Australia.

Drug user groups themselves may change and evolve, initially having focused on specific roles but over time developing a stronger cohesion and wider sense of purpose.

It is also possible to look at drug user self-organisations from a process perspective. This approach sees groups providing a point of shared reflection within a local drug using community. This is illustrated in Webster's Community Development Cycle⁵⁸, which shows the potential of a continual developmental journey informed by life experience.

Figure B: Community Development Cycle:



⁵⁸ Webster G (1989) *Community development and health promotion – links between theory and practice* Public Health Alliance Symposium

discuss potential strategies, and agree on a
course of action)

4.10 A Brief History of Drug User Self-Organisation:

The 1970s saw the 'spontaneous' formation of two key drug user self-organisations. The first was the 'Junkie Bond' developed by drug users in the Netherlands to lobby politicians and the media about the treatment and misrepresentation of drug users⁵⁹. The second was the 'Committee of Concerned Methadone Patients and Friends inc.' (CCMP), which was formed by Methadone patients in 1973 affirming the importance of advocacy for those in drug treatment programmes.⁶⁰

These two early examples of drug user self-organisations, also illustrate the two main streams of drug user organising:

- The development of interventions and the fostering of healthy communal beliefs, values and patterns of behaviour within illicit drug scenes.
- The service users and patients rights movements.

The advent of HIV marked a significant period of development for drug user self-organisations. In particular, this period saw the promotion of drug user groups by sympathetic professionals in Australia and New Zealand using a model described as 'contrived spontaneity'.⁶¹ This model reflects the role of professional allies or facilitators in stimulating the growth of drug user self-organisations. These can go onto to become as equally self-determining as those groups that started in a more spontaneous form. At the point of writing, drug user self-organisations exist on every continent of the world with the exception of Africa.

⁵⁹ McDermott P (****) *Will drug users respond to the challenge?*

⁶⁰ Woods J (****) *Advocacy and the voice of the consumer*

⁶¹ Byrne J (1999) *Done to, done over, doing it for ourselves - The history of the drug users movement*
Black Poppy Magazine Issue 3

The history of drug user groups in the UK and Channel Islands had remained somewhat haphazard with individual groups coming and going before the formation of the National Drug Users Networks in 1999. The National Drug Users Networks is a coalition of two types of drug user self-organisations:

- Local Drug User Groups – those with a locally focussed geographic remit
- Special Interest Groups – networks or organisations operating in the national arena with a specialist focus (i.e. drug treatment, Hepatitis C etc)

The National Drug Users Networks has provided the legitimacy for discussions with Government and senior policy makers. This has led to improved user representation in national discussions on drug treatment and blood borne viruses, and better representation between national professional drugs organisations and the drug users movement.

The vast majority of drug user groups in the UK are small in size, their structures are fragile, and they are poorly resourced. Some have yet to secure a role and function beyond a point of shared reflection for a group of local drug users. However, these groups can still provide a contact point with the local drug using community and a foundation from which a more defined group can develop.

Despite the emerging nature of the drug users movement, much valuable work is being done, new institutions and networks have been established, and some strong links have been secured with the professional drugs field. This context potentially provides the foundation for future development, wider representation, and more secure self-organisations.

4.11 The Search For ‘Reasonable’ Drug User Self-Organisations

A significant theme in the professional support of drug user self-organisations is the search for ‘reasonable’ drug user groups or representatives. This has led professionals to withdraw their support from drug user self-organisations because they are seen to be unreasonable, too angry, or too militant. Professionals either try to dismiss the relevance of these drug user self-organisation, challenge their legitimacy, or offer other groups of drug users the chance and resources to self-organise as an attempt to offset the criticisms of the existing drug user self-organisation. This latter approach will normally be based on forming a service user group with the hope that a restricted focus will keep the drug user group in ‘safe’ territory.

This is a difficult and usually counter-productive approach. Over time drug user self-organisation will link together with their peers⁶². There is substantial anger among drug users at the range and quality of drug services, with drug policy, and with wider issues of social exclusion. It would be wrong to say that all drug users share the same views. However, it is unjust and against all the principles of community participation to seek to suppress views that are uncomfortable or contradict the views of professionals or politicians.

⁶² National Drug Users Development Agency (2001) *Drug user involvement – The Scottish experience. History, analysis and the way forward*. National Drug Users Development Agency

The limited history of engaging drug users in the UK has led many to bottle up their anger and frustration so that when first engaged these feelings can be explosive. However, over time, and with a commitment to inclusion, this historic reservoir of feelings can be drained and a more constructive engagement is enabled. The real challenge for professionals is to see this as part of the developmental process and not to take comments personally. When professionals seek to cap or stem the flow of this initial expression anger and frustration, this leads to a severe fracturing of relationships. This will inevitably exacerbate the problem. It is only through positive inclusion that these feelings will be reduced and drug user self-organisations will grow to have clearer understanding of the funding or policy restrictions faced by drug services.

4.12 Section Summary

This section has identified the range of drug user groups. These fulfil roles functions that can provide important contributions to the tapestry of local services.

Some drug user groups will neatly fit into one category, while other will have multiple roles. Others may develop and change their roles over time.

Services have a role in supporting drug user self-organisations but need to show care in defining and negotiating this role.

Some functions of drug user self-organisation, and some forms of recreational drug user groups, will sit outside the professional service environment.

5. Employing Workers To Support User Involvement, Peer Support And Drug User Self-Organisations

5.1 Professional Facilitators

Roles

Professional facilitators are people employed to support drug user organising. They are increasingly being employed in England as 'User Involvement Workers'. These may have a remit to stimulate particular forms of drug user organising or to support drug user involvement and drug user self-organisation in a particular area. It is most helpful when these post holders are given sufficient scope to allow bottom-up community development work with drug users.

Location

It is very important that care is taken in locating professional facilitators in the spectrum of local services. Linking a district-wide post to any one team may play into interagency rivalry. In fact, attaching a professional facilitator to any drugs team can in itself be problematic given the potential conflict of interests.

It is not impossible to locate professional facilitators alongside drug services but significant caution should be shown. Such an approach has led to:

- Drug users to seeing these professional facilitators as agents of drug services.
- Professional facilitators attempting to foster replacement representatives and groups as part of an attempt to sideline or undermine existing 'unreasonable' drug user self-organisations (see Section 4.11 'The Search For 'Reasonable' Drug User Self-Organisations').
- Professional facilitators becoming overly focussed on drug work agendas (i.e. one facilitator who formed a new local community drug team while employed to support a local drug user group).
- A drug professional to be removed from a multi-disciplinary team after championing user involvement.
- Significant conflict between senior management, who supported user involvement, and senior professional staff, who experienced this approach as conflicting with traditional models of addiction and undermining professional autonomy.

Alternative options that have been successfully applied include:

- Linking professional facilitators to established national or regional drug user groups.
- Attaching professional facilitators to generic community development agencies or patients' rights organisations.
- Contracting the work out to non-service providing drug teams such as drugs education teams that draw their staff from youth and community backgrounds.
- Employing the professional facilitator through the local health promotion unit, particularly if the unit has experience in community development or peer support work. This approach was successfully applied in securing the community approach of the North East Essex Outreach Service.⁶³
- The professional facilitator is linked into the wider management structure of the service, rather than a direct link with any one services (i.e. Trafford Substance Misuse Service). This requires a clear commitment from the senior management to user involvement.

An alternative option might be to link the professional facilitator to local joint planning structures for example working alongside a DAT Co-ordinator. This reflects the important relationship between those planning and commissioning services and the consumers of services. Care still needs to be taken ensure autonomy but a number of positive relationships have developed between drug user self-organisations and DAT Co-ordinators.

Recruitment

Given that many clinical drug workers may not possess the skills necessary to undertake this type of facilitation work, it is important to consider advertising outlets and the person specification carefully. The following people are likely to have the knowledge, skills, and experience for this type of work:

- Community development workers
- Youth workers
- Those from self-help movements
- Health promotion workers with a specialist interest in community and peer-based models
- Those from the patients' rights or consumers movements
- Outreach or detached workers with a track record in community models

Where there are drugs specialists with the above skills then this is obviously helpful. However, given the current skills mix in drug services, it may be sensible to prioritise people with the appropriate facilitation and process skills rather than seeking drugs specialists.

As the drug users movement matures and develops in the UK, there is likely to be a growing body of drug user activists who may also be able to apply for such positions. The National Drug Users Development Agency can help advertise posts through their internal structures, as can the range of drug user magazines.

⁶³ Bolton K and Selleck S (1991) *Out on your own: making solo outreach work* Druglink

Timescales And The Journey To Self-Determination

The challenge for any professional facilitator is to know when to shift their role and encourage the transition to self-determination. It is the sign of a successful project that drug users develop the necessary skills and aspire to lead their own self-organisations. Equally, it is important not to withdraw professional support too quickly. Succession planning is an important part of the developmental cycle.

Too often timetables are defined by short-term funding. Good practice would determine that user facilitation posts should be funded for a three-year period. This is the usual period which it takes for community based initiatives to become established and to reach the 'lift off' point⁶⁴.

However, the professional facilitator may change their role and work focus during this time moving from an initiator, to a development worker, and finally becoming a consultant and mentor as the life cycle of the project progresses.

Having a funded professional facilitator should prevent the move towards funding peer development worker or group co-ordinator (see Section 5.3). A number of experienced drug user activists have left voluntary work to seek paid employment and this has inevitably undermined a number of drug user self-organisations. While a project may be funded for three years, it may be appropriate to have renewable contract with the professional facilitators in case self-determination is achieved prior to this time.

Management Issues

If posts are located in drug services or generic community development agencies, it is likely that line management will not contain expertise in the process of facilitation and in specialist drugs work. The need for non-managerial supervision, consultancy, or a specialist advisor should be built into the funding of the project. This might relate to the professional facilitator alone or to the wider project, including the line manager.

One of the potential challenges for professional facilitators is managing aspirations of drug user groups or activists that move beyond health or social goals. Another dimension of this issue is where the professional facilitator seeks to introduce a political dimension into drug user organising. Hening and colleagues provide a helpful clarification of appropriate boundaries in their discussion of outreach work in a youth and community setting. 'A detached worker does not set out primarily to change society to fit the young person but to help the young person achieve a high resilience so that he can cope and where appropriate, effect change himself.'⁶⁵ Given public debate on drugs policy it is quite understandable that drug users aspire to contribute to this debate. However, there needs to be clear ring fencing of resources and staff time to avoid difficulties with the laws surrounding charities and the validation of funding allocated for health, and social purposes.

⁶⁴ Health Education Authority – HEA (1994) *The MESMAC Guide – A practical resource for community based HIV prevention with gay and bi-sexual men and other men who have sex with men* HEA

⁶⁵ Hening M et al (1977) *Evaluation of Detached Youth Work* National Youth Bureau – Occasional Paper 17

Case Study – Sandwell Advocacy

The Sandwell Advocacy Project is a generic community development agency working in the West Midlands. They were contracted to stimulate user involvement among drug users in the local area. They appointed a worker with experience of self-help in the gay community. While he did not have specialist knowledge about drug issues, he was an expert in the process of community organising. He addressed his knowledge gaps by meeting with a number of national drug user self-organisations looking at issues of drug treatment, Hepatitis C and specialist issues relating to working within drug using networks. The professional facilitator brought specialist skills in terms of fund raising, project management, and knowing local systems.

The professional facilitator benefited from the support of a local drug using peer leader who was already involved in Sandwell Advocacy. This provided important credibility for the project as well as offering invaluable privileged access into the local using community. Professional access points were also used, although one agency was unwilling to support the initiative and was suspicious of its motives.

The work of the professional facilitator supported the development of a local café for drug and alcohol users.

5.2 Paid Advocates

Roles

Paid advocates are employed to support drug users in their use of health and social care services. Paid advocates will usually be linked to drug treatment services. Others may have a wider role to relate to drug users more generally, supporting them in their use of specialist drug service and other health and social care provision (i.e. maternity services, dental services, general practice, etc).

Paid advocates will take a caseload of people who are experiencing problems with a service. The goal is to support them to either engage in a process of conflict resolution or take out a formal complaint. This is most often around drug treatment or other medical interventions but could equally be about interpersonal differences with staff members, breaches of confidentiality, or other perceived unfair treatment.

On occasions, paid advocates will also have a remit to develop a peer-based advocacy network of volunteers and this role impacts on the process of drug user organising. In such schemes, the peer advocates will usually manage less complex or routine cases with the paid advocate taking over more complex or specialist cases. In addition, the paid advocate will usually provide training, supervision, and advice.

The Methadone Alliance runs courses for drug user activists in peer advocacy. The aim of the training course is to equip people to respond to the most frequently identified concerns of those seeking advocacy support:

- Problems obtaining effective Methadone treatment
- Disciplinary discharge procedures
- Problems related to supervised consumption

More complex cases are then referred to the paid worker at the Methadone Alliance.

Location

Paid advocates will often be based in, or have access to office space close to, the main service to which they relate. However, ideally this work should not take place inside the agency itself, as this could prove intimidating for those seeking advice.

These posts can be usefully linked to:

- National drug user self-organisations (i.e. The Methadone Alliance)
- Patients rights or advocacy services
- Community Health Councils
- Peer-based advocacy groups (i.e. local drug user self-organisations)

Another option is for the paid advocates to work alongside the local DAT Co-ordinator.

Recruitment

There are two models of peer-based advocacy:

- In the ‘spontaneous’ approach, service users come together to form voluntary advocacy groups that may over time seek funding for professional posts.
- In the ‘contrived spontaneity’ approach, a paid advocate is employed with a remit to stimulate peer-based advocacy, in addition to providing a direct advocacy service.

The ‘spontaneous’ approach will normally see the peer-based advocacy group seeking funding for one or more of its drug user activists. Alternatively, a post may be advertised exclusively among this core group (an internal advertising approach).

In the ‘contrived spontaneity’ model, it is likely that posts will be externally advertised. Applicants may be sought from generic advocacy, patients’ rights or consumer protection backgrounds.

Management Issues

The danger for any advocacy project is that they lose their position as an ‘honest broker’.⁶⁶ It is hard for professionals to hear complaints that might be seen as a challenging to a staff member’s professional standards, commitment, or practice.

The drugs field has a range of different models and professionals may hold strong views about the type of services they want to provide to their patients. In many ways it is this context, and the current low level of complaints from service users, that emphasises the importance of independent advocacy services and a clear statement of patients’ rights.

Establishing clear lines of communication between advocates and the senior management and professional heads of local drug treatment, can help services identify themes and developmental issues. It is also valuable as a means for defusing any negative feelings that might build up within services about advocacy work. It can be helpful to have an independent chairperson for these meetings such as someone from the local public health department.

Advocates obviously require operational management, which should be secured through their employing organisation. Where the expertise of the employing agency is advocacy work then securing access to independent specialist advice on drug treatment is important for the effectiveness and credibility of the staff member. The Methadone Alliance, through its staff, Executive, and patrons, is a credible source of advice.

⁶⁶ Nelles B (2000) *Honest brokers – The role of the Methadone Alliance* Methadone Alliance – Conference Report ‘Expanding and Exploring Treatment Options’

Case Study – Methadone Alliance

The Methadone Alliance received a series of telephone calls from people receiving treatment in the Midlands. The complaints centred around the introduction of supervised consumption, which had recently started in the area without advance warning. Volunteers from the Methadone Alliance gave all callers information and advice about supervised consumption, and the General Secretary wrote to the local providers seeking clarification of the situation.

At the Methadone Alliance, it was decided that the situation would benefit from professional advocacy so the cases were referred to the General Secretary. With the help of a locally facilitated group for people in treatment, the General Secretary met with local users, as well as with the local service providers, and representatives from the relevant Health Authority.

The Methadone Alliance asked local providers to provide a mechanism to enable patients who felt unfairly inconvenienced by supervised consumption to review this practice. The local Health Authority and the local treatment providers agreed to this, and they worked closely with the General Secretary, forwarding a letter from him to every patient receiving methadone. This letter advised people who were experiencing problems with the new system to send in a tear-off slip asking for their supervision to be reviewed.

The local provider to examine these complaints formed a small group. The General Secretary from the Methadone Alliance met with all those who complained, and attended all the review meetings.

As a result, nearly half the clients were able to arrange a satisfactory transition back to take-home doses. Other clients whom the providers felt needed to remain on supervised methadone were given explicit information about what steps they needed to take. The involvement of a professional advocate helped to clarify the issues of supervision policy to both the clients and the staff of local services. As a result, more flexibility was introduced into the prescribing system as well as improved written information for clients.

5.3 Peer Development Workers / Group Co-ordinators

Roles

Peer development workers or group co-ordinators are those employed to work specifically within or alongside drug user self-organisations. These may be employed by national drug user self-organisation to support clusters of drug user groups. Alternatively, they may be staff co-ordinating larger, more established drug user self-organisations.

Location

These post holders will normally be based within the offices of their own drug user self-organisations. Where office facilities are not available people might work from home or may be based in a partner agency.

Recruitment Issues

These workers will often be the initiators or senior players within an existing drug user self-organisation. They will often have worked on a voluntary basis for a period of time prior to seeking employment. If there is only one post, but a number of volunteer drug user activists, then an internal advertising model can be applied. This restricts applications to existing members of the group but ensures a fair process of competition between group members. There needs to be a balance between equal opportunities in its strictest sense and fairness in relation to rewarding those who have pioneered drug user self-organisations.

Having an external person on the interview can guarantee fairness among a close group of drug user activists.

Management Issues

Peer development workers or group co-ordinators will be funded to provide development capacity to a growing drug user self-organisation. The staff member will either be employed by the drug user self-organisation or the post holder may be linked to a local sympathetic organisation to work with the drug user self-organisation.

Where development support is being provided to a cluster of drug user self-organisations, a lead agency will need to be identified to manage the post holder. This might be a national drug user self-organisation (i.e. The National Drug Users Development Agency, The UK Assembly on Hepatitis C, or the Twelve-Step Fellowship).

Support Needs

Those drug user self-organisations that have reached the point of employing staff are likely to have achieved a reasonable degree of autonomy and organisational development. However, employing staff may be a new challenge and professional service may offer help with model job descriptions, advice on the interview process, and access to human resource services.

Case Study – National Development Worker National Drug Users Development Agency

The first National Development Worker of the National Drug Users Development Agency undertook the role on a unpaid basis. This volunteer worked with other senior drug user activists to form the systems within the National Drug Users Development Agency, secured a working Management Committee, and led the search for core funding.

Comic Relief allocated a £250,000 fund to support drug and alcohol self-organisation in 2000. In addition, to offering a small grant of £3,000 to drug and alcohol self-organisations, Comic Relief allocated £30,000 to the National Drug Users Development Agency. This allowed for the appointment of a National Development Worker who could provide advice and practical support to those groups funded through the Comic Relief scheme.

The volunteer post holder made it clear that he would not stand for paid position. It was agreed to advertise the post internally within the drug users movement given that an expertise in drug user organising was an essential criteria on the person specification. The post was advertised in three ways:

- Through drug user magazines
- Through the Mailing List of the National Drug Users Development Agency
- Through the email lists of the National Drug Users Development Agency and the international a drug users movement

The Management Committee agreed a recruitment process. The Senior Grants Officer from Comic Relief was invited to join the Chairperson of the National Drug Users Development Agency and another Management Committee member on the interview panel. An equal opportunities approach was applied to both the short listing and interview process. The external interview panel member played an important role in securing objectivity in the interview, as the two Management Committee members knew all the candidates.

The National Drug Users Development Agency contracts out parts of its payroll service to a specialist company. The Chairperson of the organisation provides supervision to the staff member with additional support coming from other members of the Management Committee. Both the National Development Worker and the Chairperson have dual backgrounds in the professional drugs field and the drug users movement.

This post has been vital to demonstrating the capability of drug users to identify and share best practice through peer networks.

5.4 Employing Staff From Drug Using Backgrounds

Roles

Drug workers from drug using backgrounds have been employed within drug services⁶⁷ but many services have operated with a two-year drug free rule. The interpretation of this rule has varied significantly but it has served to keep drug workers who are active drug users, or on substitute programmes, away from employment in the drugs field.⁶⁸

However, ex-drug users have been employed in the drugs field. A number of reasons can be cited in support of this approach:

- In the period when the primary function of drug services was to encourage drug users to achieve drug free status, ex-drug using drug workers had relevant expertise linked to their life experience.
- Visible role models reinforce the fact that change is possible.
- Ex-drug users can also support their non-drug using colleagues to have a better understanding of the benefits and challenges of achieving and sustaining abstinence.
- Ex-drug using workers may have shared experiences or personal insight that supports them to develop a heightened sense of empathy.

Now that drug services have wider public health and crime reduction goals, a wider range of role models seem appropriate. Drug using workers might appropriately work in services with harm reduction goals, such as needle exchanges, methadone clinics, and outreach services. Here the reinforcement may be around changes to reduce harm, secure stability, and move away from offending behaviour.

Recruiting or developing drug users from the local community offers the additional benefits of privileged access and is a strong marketing tool for the service as a whole.

Recruitment Issues

The two-year drug free rule has left many drug users believing that there is little or no room for them in the drugs field. Services wishing to open their door to the best candidate, regardless of their personal drug use, will need to actively state this in adverts.

⁶⁷ Nelles B (1999) *Straight from the heart – the experience of drug user working in mainstream drug services* International Conference on the Reduction of Drug Related Harm (Jersey)

⁶⁸ Foster J (2001) *Working Junkies* Presentation to the International Conference on the Reduction of Drug Related Harm

Employing drug workers from drug using backgrounds does not need to be restricted to changing employment policies. It can be about offering drug users a developmental pathway into drug services. This is necessary if drug services are to offer a meaningful chance to those who may have been outside formal education and employment for some time. This may be engaging drug users through user involvement projects, training them as volunteers, and sponsoring them to engage in adult learning. Where such a comprehensive approach is offered, it is clear that drug users can develop themselves to become successful drug workers.

Where there is a pool of drug using volunteers within a service, an internal advertising process can be applied. In this approach, the 'internal applicants' will be given a chance to apply for a vacant position. They will still need to meet the person specification and demonstrate their capability for the job. Where no appointment is made the post can be put out for external advert. This is about creating a genuine pathway for drug using volunteers into formal employment. It also avoids the danger of volunteer schemes stagnating and losing credibility with other local drug users.

Support Needs

The only real concerted attempt to engage drug users as workers was in relation to HIV Outreach Work. As has been stated previously this work was often poorly designed, delivered and managed. An assumption was made that the life experience of drug users alone would equip them to be effective drug outreach workers. Given that many drug using outreach workers were employed away from their own local drug using communities, they did not even have the benefit of privileged access.

Workers from drug using backgrounds need to be appropriately skilled and supported in their work. At the same time, they also need to be provided with appropriate development support and held within appropriate operational framework. DrugScope and the National Drug Users Development Agency are currently producing new guidelines on employing drug workers from drug using backgrounds. The intention is to create a safe and supportive environment within which drug workers from drug using backgrounds can be employed with confidence for all parties.

Where workers from drug using backgrounds have to hide their drug use, this can create difficulties for the staff, their colleagues, and management. Effective workplace policies are widely applied in relation to alcohol and these offer a model that can be developed in relation to illicit or prescribed drugs.

Case Study – Healthy Options Team

The Healthy Options Team (HOT) is an innovative harm reduction team based in the east end of London that is part of the NHS. It works to a community development model and has a strong ethos of user involvement. HOT is a hard to reach team applying a range of models to improve access to the most marginalized and socially excluded sections of the drug using community. Its low threshold approach is recognised as a model of good practice

Part of this approach has been the employment of people from drug using backgrounds.⁶⁹ HOT openly states its employment approach in job adverts and gives recognition to life experience within person specifications. Staff from drug using backgrounds are expected to reflect during the interview process on their capacity to manage their drug use in order to be effective practitioners. The aim is to sustain an open dialogue that provides a supportive environment to staff but equally reinforces their responsibility to be effective in their work role.

HOT's approach is not just about employing people from drug using backgrounds. It also extends to actively providing a development path for people from the local drug using community. The service operates a community student scheme, within which drug users are offered placements, workplace training, and are sponsored to attend external courses.

Alongside staff from drug using backgrounds, HOT employs staff from more traditional NHS backgrounds. This skills mix allows for an important dialogue within the staff team, allowing those from drug using backgrounds to draw on the specialist skills and knowledge of their colleagues. At the same time, it allows staff from traditional backgrounds a chance to gain insight from the life experience of their colleagues. This has led to innovative work among the nursing staff both in terms of specialist models of practice⁷⁰ and in terms of nurse training.⁷¹

There are no special employment policies for staff from drug using backgrounds. Performance, timekeeping, and sick leave are all managed within the framework of the Trust's competency and sick leave policies. Obviously staff from drug using backgrounds need to take care not to bring the organisation into disrepute. This offers protection against staff becoming involved in dealing, using illicit drugs on the premises, or engaging in other criminal activity. Any problem issues can be addressed with a greater degree of safety when staff can talk openly about issues when drug use is not a dismissible offence.

All staff members are trained in Motivational Interviewing and this acts as a core therapeutic approach for the team. The model encourages all staff to motivate service users/members to achieve their own goals within a client centred model, while reducing the potential for either rescuing or punishing approaches. Motivational Interviewing also provides a common language within the multi-disciplinary team.

Staff from drug using backgrounds and from the local drug using community provide valuable role models to service users. They also have good privileged access and shared insights with the local drug using community. This serves to create a strong connection between the team and the drug using community. Service users have described this as being like a 'family'.⁷² This is a markedly different from the 'mutual antagonism' that characterises many services relationship with their clients.⁷³

⁶⁹ Bath N ***Community Student Scheme paper*** Presentation to International Conference on the Reduction of Drug Related Harm

⁷⁰ Elward J (1992) *HOT pursuit* Nursing Times Volume 88 No. 48

⁷¹ Phillips P and Hassan A (1997) *Valuing users' experiences in substance misuse nursing education* Mental Health Practice Volume 1 No 4

⁷² Daker-White G (1992) *Consumer evaluation of Healthy Options Team – Results of pre-feasibility study* Unpublished

⁷³ McDermott P (2002)

5.5 Section Summary

As drug user organising becomes more established, it is inevitable that more staff will be employed as specialists in this area. Initially, it may be necessary to recruit people from outside the drugs field in order to access specialist skills and experience. However, over time it is likely that more drug specialists will be available with relevant skills and expertise. These are likely to come from both from the professional drugs field and the drug users movement.

6. Running Events For Drug Users

6.1 Introduction

There are two different types of events that can be run to engage drug users:

- Events targeted specifically at drug users (i.e. a user consultation event).
- A more general event seeking to engage drug users alongside others interested or involved in the drugs field (i.e. a local Drug Action Team Conference, a conference on drugs policy or practice, or a local training event on drugs issues).

This section offers advice about running this type of event in order to strengthen the engagement with local drug users. This section draws on the experience of the National Drug Users Development Agency who have worked with a number of conference organisers to improve access for drug users. The National Drug Users Development Agency has experience of running their own meetings for drug user activists. Obviously, the size and range of any event will inform what advice should be taken from these guidelines.

It is perfectly legitimate for drug services, either on a national basis or locally, to seek to engage a body of drug users beyond those involved in formal drug user self-organisations. However, drug user self-organisations can still be important partners or consultants to such events. Where drug user groups are excluded from those events then this is more likely to create the perception that there is a hidden agenda to undermine the authority of a local drug user self-organisation. Engaging drug users in such events can help them developmentally, allowing them to broaden their membership or activist base, and thus enhance their legitimacy. It may also open the group up to a wider range of perspectives and insights from the local drug using community.

6.2 Target Audience

In defining the target audience, services need to be clear about the nature and purpose of your event. For example, if the intention is to consult drug users about the range and quality of local drug treatment provision, then the target population is defined as service users within a particular catchment area.

It is equally important to be clear about why this event is of value to the target audience. It is easy to see the value of an event to a service and therefore to expect drug users to attend on this basis. Often an event will have value to both professionals and to drug users but these may be different. This would need to be taken into account in advertising or marketing the event.

Where there is a desire to engage drug users more systemically in a local area, it is important to demonstrate the longer term value of an event to drug users. For example, a local authority sought to engage drug users in a consultation process about its annual drugs strategy. It approached a local drug user group for support in reaching its target audience. In the first year, twenty drug users attended the consultation session. By the second year this had fallen to five users, and in the third year the drug user self-organisations refused to support the local authority in advertising its event. The local authority was genuine in wishing to consult drug users about its annual strategy. However, local drug users did not see any changes to services after their comments. Such experiences lead people to become cynical about the process and to view it as a 'tick box' exercise.

6.3 Advertising

Once the target audience is clearly defined, it is possible to begin planning how to reach them. This first step is to be clear about the possible contact points between the target group and professional services. This can lead to a number of professional advertising approaches:

- Posters in drug agencies
- A letter sent out to the service users of a particular agency
- Flyers sent out alongside the dispensing of methadone or other substitute prescribing options
- Direct engagement between drug workers and their service users

Drug user groups have been both partners in and added their endorsement to events run by professionals. This endorsement will usually affirm the 'user friendly' status to other drug users. Factors that would identify an event as 'user friendly' might include:

- The availability of free or subsidised user places (for paying events).
- The inclusion of user activists as speakers or workshop facilitators.
- Space for a drug user stall at the conference.
- A closed session for drug users to meet at the end of the event.

In return drug user groups agree to actively advertise the event to their peers. This might include:

- Mail outs through the drug user self-organisation membership schemes.
- Advertising through drug user magazines or newsletters.
- Advertising through peer networks. Particularly through local events, this has included distribution through friendship and illicit commercial networks.

The peer endorsement will usually be reflected in conference materials.

The endorsement of peer leaders should not be underestimated. The National Drug Users Development Agency was asked to consult on and provide a training event for drug users and drugs professionals on the South Coast. Given that this was an area with no existing drug user activists, only professional advertising mechanisms could be used. Despite widely advertising the event only two drug users attended. These drug users confirmed that the advertising had successfully penetrated drug-using networks, but there remained a deep, if unfounded, suspicion about the nature of the event. Many had stayed away on this basis.

6.4 Incentives / Payments

Offering financial incentives has been shown to be successful in engaging drug users in research programmes.⁷⁴ There are cost implications beyond travel expenses for drug users attending an event. Some drug users will be employed and may have to give up a day's work to attend. Other drug users may be engaged in the illicit market and may need to raise money to support their illicit drug use. This forces people to make hard economic choices about the value of attending an event.

Even small payments can make a difference in the recruitment to events. Some balk at the idea of giving cash to illicit drug users as this is thought to be tantamount to buying them drugs. The alternative is to offer people vouchers for local supermarkets or other retail outlets. Those drug users who are committed to spending their money on illicit drug use will exchange them for cash on the illicit market and in this conversion the drug user will lose money. The effect is to reduce the incentive for the drug user to come to the event.

6.5 Knowledge Levels Of Participants

When you are running an event that seeks to engage drug users, it is important to be aware of their knowledge levels. Drug users bring expertise about their experience of being a drug user within a local area, and about their engagement with local services. They may, however, have limited understanding of the funding, organisational relationships, and planning process within drug services. There are experienced drug user activists who have very good insight into all of these issues but this should not be generalised to all in the drug using community.

In planning any event, it is important that people are provided with the necessary background information to enable them to properly participate. For drug user only events, there might be a background briefing session to allow drug users to understand the context of the area on which they are to be consulted. For shared events with professionals, it can be helpful to have an access session before the event to offer drug users the chance to get up to speed with professional participants.

⁷⁴ Broadhead R *****

It can also be helpful to assign mentors to individual or groups of drug users within an event. These mentors would support their mentees through the conference or training event. These mentors might be sympathetic professionals or more experienced drug user activists. The key is to ensure that drug users are well enough briefed and supported to ensure that they can offer their expertise and insights to an event.

6.6 Timekeeping

It is important to be careful about making generalisations about any population. However, it is fair to acknowledge that managing timekeeping can be a significant issue when working with dependant or street drug users. There are a number of possible explanations for this:

- People's health being compromised (HCV, HIV etc), which makes them slow starters in the morning.
- People's sleep patterns being orientated towards late nights and late mornings.
- People picking up prescriptions first thing in the morning, which is becoming increasingly a significant issue with the increased use of supervised consumption and restrictions on 'take outs'.
- The need to secure illicit drugs, and possibly the funds for illicit drugs, before contemplating departing for an event.
- There are often incentives for people to travel outside rush hour times. People on low incomes may prefer to travel after 9.30am. These issues need to be factored in particularly where travel warrants are not being issued.
- Drug using parents may be responsible for taking their children to nursery or school.

In addition, other issues may intervene to make people unreliable attendees at events:

- People may be living reasonably unstructured lives and therefore forget when an event is actually due to take place, despite meaning to attend.
- People may have very restricted access to money or their access to money may fluctuate from day to day. Even when travel costs will be reimbursed, many drug users will not be able to afford to buy their tickets in advance.
- People may face life crises, drug crises, and legal emergencies (i.e. being arrested on outstanding warrants as they pick up their Methadone).
- Drug using parents may rely on friends or family to provide them with childcare support' and this may break down. Even when children are in school there are times when children will be off school.

There are a number of practical strategies that can be considered to manage timekeeping and variable attendance:

- It is important to plan an appropriate start time that reflects early morning challenges and commitments. It is useful to open with an hour registration slot. This will also allow for informal introductions and reduce the impact of late arrivals the first formal session of the event.
- For national or regional events, it can be helpful to offer overnight accommodation the day before an event, most helpfully in or alongside the training venue itself.
- For people who are in drug treatment, it is important to support the process of securing 'take out' doses, in order to remove the pressure of picking up prescriptions on the morning before an event.
- Providing people with tickets in advance of the event is valuable if labour intensive. Expecting people to fund their travel expenses up front places a major obstacle in the way of those on low incomes.
- Another approach is to co-ordinate travel arrangements. Again, it is important to avoid an early start, to build in time to allow people to be woken up, and for latecomers to be chased up.
- It can be helpful to negotiate the type of support someone might need to help them attend an event. This might include an early morning call or text message.
- It can be helpful to allow people to turn up on the day and register. This will allow people to bring friends who are interested at the last minute. This is likely to be offset by dropouts among confirmed places.
- Allow people to have ownership of their place and to be able to offer this to another drug user if they are unwell or otherwise unavailable on the day.
- Give advanced notice for the event but then provide more immediate reminders and follow-ups. Many people mean to come to events but just forget because they are living on a day-to-day basis.
- Making childcare arrangements within training events can help to secure the attendance of the drug using parents.

6.7 The Role Of Speakers, Chairs Or Facilitators From The Drug Users Movement

Engaging drug users formally in the running of events gives a public declaration about the value and worth of the expertise held by drug users.

For any event to work successfully, it will need to be effectively managed and kept to task. Also it is important that the more outspoken drug users do not dominate sessions at the expense of other quieter but equally legitimate voices. Professional chairs or facilitators may be perceived as seeking to suppress views that are uncomfortable or difficult to hear when in fact the point has been made and the session needs to move on. Chairs and facilitators from the drug users movement may find this process easier as the perceived power balance in the session is likely to be different.

Speakers from the drug users movement have four main functions:

- To provide personal testimony about their experience of using drugs or drug services.
- To report back on work undertaken in drug user self-organisations (i.e. peer support projects, consultation exercises, advocacy work etc) or on the general progress of drug user organising.
- To provide a conceptual or policy framework to drug user organising in all its forms.
- To offer drug user perspectives on national policy and practice.

People speaking at events will often be chosen on their track record or the merits of an abstract. National or local drug user self-organisations can help identify people with the necessary skills who may be less well known. It is also helpful to structure events to allow people to develop these skills through workshops or presentations to small groups within a larger event.

6.8 Sustaining Contact

You can work very hard to engage a group of drug users in a consultation or training event, only to undermine this work by failing to follow up effectively once the event is over. Many drug users believe that services are not really interested in hearing their voices and that user consultation is a tokenistic exercise. In reality, the information gathered from drug users may impact significantly on local policy and practice. However, in terms of future user involvement in events, this main concern is whether drug users believe that they have had any impact policy and practice. Where this is not immediately apparent to service users then it is important to explain the background work that is being done and timescales for change.

There are a number of ways that you can sustain contact with attendees beyond an event:

- Each attendee can be sent a thank you letter for their contribution and attendance shortly after the event. It is best that these are personally signed rather than looking too much like a standard letter.
- A summary of proceedings can be produced, hopefully within a few weeks of the event. This should include things that are going to happen and the timescale within which change should be expected. This allows attendees to be clear what was agreed and to know when change should be expected.
- Linking people up with their local drug user group, encouraging them to join the National Drug Users Development Agency mailing or email list, and offering them the chance to subscribe to drug user magazines, can all help tie participants to the wider process of drug user organising.
- You may wish to set up a follow up event in which those doing the consulting give feed back to the target audience about progress and any proposed changes.
- Producing the summary document in newsletter format allows the event (particularly a consultation event) to reach beyond the initial audience. Hopefully this will inform and encourage other drug users to attend future events. Including one or more user perspectives of the event in the newsletter will help bridge any residual suspicion.

- The local or specialist press may also be willing to cover the outcome of the event. The Big Issue for example provided good coverage to the National User Consultation Conferences run by the NTA in 2002.⁷⁵ Such media interest puts the process into the public domain and also encourages a wider audience of drug users to see that the event was serious and had an impact.

6.9 Case Study – UK Assembly on Hepatitis C Conference

The UK Assembly on Hepatitis C ran a conference in 2001 for people living with Hepatitis C. The aspiration was to reach beyond the core membership of the self-help groups.

The event was advertised through:

- The member groups of the UK Assembly,
- Mainliners Newsletter
- The mailing list of the National Drug Users Development Agency
- Drug user Internet lists.

In addition, the conference organisers visited websites specialising in Hepatitis C and sent email invitations to people registered in the guest books. Also adverts for the event were placed in these website guest books.

Once people had registered for the conference, they were sent regular reminders to promote attendance at the event. People were sent train tickets in advance of the conference and people were able to register on the day.

The event set out to support and encourage self-help among people living with Hepatitis C. The aims included:

- To develop skills and improve knowledge among the audience
- To offer the chance for people to exchange information
- To encourage self-organisation

Given the compromised health of many of the participants, the conference organisers ensured access to alternative therapies throughout the day.

Time was also made available during the day to allow participants to share ideas, swap remedies, share ideas of self-management, and network. This part of the event was given equal validity as the formal elements of the conference.

Workshop facilitators were given a template for running their workshop. The aim was to guide presentations to be focussed and on a subject and also to ensure adequate time for discussion.

The conference was a significant success attracting 120 participants from across Northern Ireland, Scotland, Wales and England with a good gender balance.

⁷⁵ Daley M (2001) ***** Big Issue

Participants were sent a report of the conference. They were also encouraged to link into the Hepatitis C movement to ensure continued contact and engagement with future events.

6.10 Section Summary

In this final section, the challenges of involving drug user in events have been highlighted. Strategies for addressing and managing these issues have been identified. There are increasing examples of events successfully engaging drug users. However, these examples required careful planning, a commitment to creating a user-friendly environment, and a desire to deliver events that were seen as valuable by the target audience.

Drug users may have special needs but when these are designed into an event then drug users will often respond positively to the opportunity. As Spear and Howell reflected after running a conference on the planning and delivery of drug services, 'the enthusiasm and bravery of the users who attended the conference shattered our stereotypes and made a mockery of our precaution.'⁷⁶

Drug user self-organisations have been identified as a resource to those designing events for, and seeking to engage, drug users.

⁷⁶ Spear S and Howell H (1995) *The Searchers* Health Service Journal

7. Concluding Comments

Drug user organising offers many benefits and opportunities to the commissioners, providers, and users of drug services. There is the potential to create a more effective dialogue between the professional drugs field, and drug users and their organisations.

Drug user involvement has long been aspired to within drug services but, unlike other parts of the health and social care sector, it has not become a reality outside a few tiny pockets of good practice. Drug user involvement has been on the bottom of the agenda within drug services and therefore has failed to receive the attention it requires. The new emphasis being placed on user involvement by the National Treatment Agency has increased the priority of this work. Services and Drug Action Teams are responding constructively at a time when new monies are available. Alongside this professional development, drug users themselves have begun to more formally self-organise and network. While there is still much work to be done, the conditions are increasingly promising.

Engaging drug users is about securing and enhancing an open and reflective culture at all levels within drug services. It is vital that user involvement is adequately resourced, but equally that it underpinned by best practice. There is also a need to expand the research base in this complex and potentially rewarding specialist area of the drugs field.

Ultimately progress in this area will be about the willingness of parties to open up new lines of communication, build trust, and to learn to hear each others views with due respect and attention.

Service Users Charter

Principles of Treatment

Treatment is a partnership between patients and their treatment team. People have a right to be actively involved in planning their own treatment, and decisions about which treatment or treatments best meet their need should be taken jointly.

Service users should be informed of all the potential therapies and treatments that are available for the treatment of their condition. Recognised substitution medications that are approved in the 1999 Clinical Guidelines should not be withheld where they are appropriate.

Services for drug dependency should work closely with services treating people with blood-borne viruses to ensure that individual patient care is integrated and draws on the resources of both clinical teams.

Services should provide both help to abstain from drug use, and also provide help to enable users to reduce the harm of their dependency and stabilise their substance use.

Urine specimens and other samples should only be taken in private. “Observed Urination” is undignified and unnecessary; it should not take place now that other techniques are available – e.g. mouth swabs.

Service users have a right to be actively involved in designing, locating, and staffing the services that provide them with care.

Service Users should be represented on committees monitoring service standards, and responsible for service development. Service users should also be represented on their provider’s Clinical Governance group and at wider levels on DAT and DRG Working Parties.

Disciplinary discharges for missed appointments or non-compliance with medication is an overly punitive sanction, and other ways should be found to address such issues. Service users facing disciplinary discharge should be offered mediation that seeks to resolve the problem. Any decision to discharge a patient should be reviewed by a Doctor.

Service users have the right to independent, locally-based advocacy services. From April 1st, all NHS Services must provide independent advocacy and mediation services as laid down in the Health and Social Care Bill 2001.

Appendix B

Standards In Advocacy Services

To be inserted after consultation period

National Organisations – Contact Details

National Drug Users Development Agency

P0 Box 33539
London E9 7YN

Tel: 020 8986 5475

Fax: 020 8525 0199

Methadone Alliance

35 Cavendish Road
London N4 1RP

Tel / Fax: 020 8374 4395

The Twelve Steps Fellowship

Narcotics Anonymous (National)
202 City Road
London EC1V 2PH

UK Assembly on Hepatitis C

c/o The National Hepatitis C Resource Centre
PO Box 31844
London SE11 4DT

Tel : 020 7735 7705

Fax: 020 7735 6645

E-Mail: advice&info@hep-ccentre.com

Website: www.hep-ccentre.com

The British Liver Trust

Ransomes Europark
Ipswich IP3 9QG

Tel: 01473 276326

National Aids Trust

New City Cloisters
196 Old Street
London EC1V 9FR

Tel: 020 7814 6767
Fax: 020 7216 0111
E-Mail info@nat.org.uk
Website: www.nat.org.uk/nat/

National Youth Agency

17 – 23 Albion Street
Leicester LE1 6GD

Tel: 01162 853700

National Magazines – Contact Details

Black Poppy

PO Box 33033
London W9 3LT

Tel: 020 8968 3452
Fax: 020 8968 3311

E-mail: blackpoppy@genie.co.uk

CC: News

PO Box 2700
Lewes
BN8 5AQ

Tel: 07788 724852

Monkey

Monkey Magazine
PO Box 108
Stretford
Manchester
M32 8FT

Tel: 0161 792 6922

Users Voice

The John Mordaunt Trust
c/o Drugscope
32-36 Loman Street
London SE1 0EE

Tel:
E-mail: RMHTSMS@dial.pipex.com