

# TACKLING DRUGS

## CHANGING LIVES

### Peer-led approaches for ex-drug users to meet diverse needs

#### A Practice Guide

October 2006





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The report was produced by UCLAN and the Project Steering Group, comprising:

Shereen Sadiq (*Aftercare Team Lead, Drug Interventions Programme, Home Office*), Sherife Hasan (*Head of Treatment, Crime and Drug Strategy Directorate, Home Office*), Allan Johnstone (*User Carer Lead, National Treatment Agency for Substance Misuse*), Ian Robinson (*Chief Executive, European Association for the Treatment of Addiction*), Chris Kelly (*DIP Programme Manager, Nottinghamshire County DAAT*), Daren Garratt (*The Alliance*), Steve Cooke (*Chief Executive, Nelson Trust*), Kum-Fong Yeung (*Aftercare Team, Drug Interventions Programme, Home Office*), Abd Al-Rahman (*Head of Strategic Development, The Federation*), Stuart Cheesman (*Northants User Involvement*), Diane Curry (*Director, Partners of Prisoners*), John Gordon Smith (*Aftercare Worker, London Borough of Hammersmith and Fulham*), Mark Payne (*National Offender Management Service, Prison Health and Offending Partnerships Drugs Strategy Unit*), Nick Barton (*Chief Executive, Clouds*).

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# Introduction and Aims

There is a growing awareness that the gains made in health, improved social circumstances and reduction in offending, which arises from successfully completing drug treatment in the community or prison, will be lost if ongoing support is not provided to drug users. It is cost-effective for the individual, their family and the wider community if these treatment gains can be sustained through the development of effective and appropriate aftercare provision in each Drug and Alcohol Action Team (DAAT) partnership area.

It is essential that DAAT partnerships develop an appropriate continuum of care and levels of support for drug users throughout their treatment journey. Support that starts when an individual enters treatment should continue throughout the time they are in treatment and subsequently into aftercare. Support and help based on shared experiences provided by ex-drug users can play an important part in the development of local aftercare provision. This support can be described as peer-led. It can include:

- **psychological and emotional support** – e.g. during the transition from user to ex-user;
- **social support** – developing new social networks in a safe environment, combating isolation and establishing alternatives to social activities associated with drug and/or alcohol use;
- **practical support** – e.g. how to access retraining opportunities or life skills training.

Peer-led support is provided in a variety of different ways across England. It is widely acknowledged that there is no single source or type of user support. Drug users will have different needs as they go through the different stages of treatment. Interventions and options that meet local diverse needs should be available to enable individuals to seek support in ways that are appropriate to them.

However, there is a lack of information on how peer-led support is best delivered to meet the diverse needs of those who have left prison or completed treatment and need help with the transition back to the community. This was a gap identified in work previously commissioned by the Home Office<sup>1</sup> on five London peer-led projects.

This practice guide has therefore been developed as a resource for DAAT partnerships and commissioners, to provide examples of practice that will support them in developing and delivering appropriate peer-led support to meet the diverse needs of ex-drug users in their local areas. It identifies transferable practice using examples of practical approaches of peer-led support in England from within the substance misuse sector, but also from associated sectors such as mental health and HIV. The limitations of this document are also acknowledged at the start.

The terms 'peer-led support', 'peer-led approaches', and 'user-led' or 'peer-led projects' are used in this practice guide interchangeably. They refer to projects or approaches that have been initiated and/or developed by people who have themselves completed treatment and are

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<sup>1</sup> *Developing peer-led support for individuals leaving substance misuse treatment: Emerging themes and findings from five peer-led support projects* (April 2005).

able to provide support based on shared experiences. The term 'substance misuse treatment system' is used to refer to all treatment organisations involved in the commissioning and delivery of treatment for substance misusers, including organisations from the statutory, voluntary and independent sectors. A full glossary of the terms used in this report can be found in Annex A.

All the case examples outlined in the report appear with the permission of the individual and the peer-led project. However, to protect their privacy, names and some details have been changed.

## Structure of this practice guide

This practice guide is divided into three sections.

Section One outlines the methods used to gather the information, and identifies the common key themes necessary to develop and deliver effective peer-led support to address diverse needs as part of local aftercare provision.

Section Two presents examples of projects and approaches that illustrate the variety of ways in which peer-led support can be delivered to specific population groups. Each example identifies:

- common barriers and problems faced;
- how peer-led support is developed;
- case studies that outline examples of peer-led projects and approaches; and
- individual examples of people who have accessed this form of support.

Section Three outlines a series of key principles that provides a framework for DAAT partnerships to take forward this area of work and plan, commission and support the development of peer-led approaches in their local area as part of their aftercare provision.

## SECTION ONE

# 1. Background

The importance of aftercare for those who have completed drug treatment is now well established. Both the National Treatment Agency for Substance Misuse's (NTA) Treatment Effectiveness Strategy (2005) and the Home Office Drug Interventions Programme (DIP) actively promote aftercare and peer-led support as key elements of the treatment journey.

DAAT partnerships have access to funding to sustain, extend or develop peer-led support. This has been made possible through grant funding which supports the delivery of DIP, a key element of the national Updated Drug Strategy. The *Grant to Implement the Drug Interventions Programme – 'DIP Main Grant'* – is now a single grant consisting of the Throughcare and Aftercare and Arrest Referral grants. The general conditions of the grant specifically require DAAT partnerships to develop support around relapse prevention and peer-led support for drug users leaving treatment.

This practice guide builds on the previous work commissioned by the Home Office<sup>2</sup>. That briefing paper focused on five London case studies and outlined how those peer-led projects had been initiated and the role of DAAT partnerships, and others in the substance misuse treatment system, in supporting their ongoing development. The findings from that briefing paper suggested the following:

- Peer-led support is a key factor in the move-on journeys of users and should be available both for those in drug treatment and for those who have left it.

- Many peer-led projects and approaches have been initiated and developed by ex-users who have recognised a need not met by existing service provision. Support and encouragement may be needed to maintain and/or develop these small local projects. Hence, an equal balance of peer and professional and organisational involvement is likely to be required to sustain and develop peer support projects at local levels.
- Valuable support already exists from networks and associations, including Alcoholics Anonymous and Narcotics Anonymous. However these approaches may not suit all substance users.

The briefing paper also highlighted the limitations in understanding need, and the necessity for peer-led approaches to meet diverse needs. This follow-up practice guide was initiated by the Home Office to outline examples of peer-led support that have been developed to meet a range of diverse needs across England, to highlight common key themes and to raise DAAT partnerships' understanding and awareness of peer-led approaches and projects. The examples used to inform this practice guide came from a range of peer-led approaches, including:

- national self-help associations such as Narcotics Anonymous;
- local peer-led approaches and projects established and delivered by ex-drug users;

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<sup>2</sup> *Developing peer-led support for individuals leaving substance misuse treatment: Emerging themes and findings from five peer-led support projects* (April 2005).

- local peer-led approaches and projects established and delivered by or with the support of service providers from the substance misuse treatment system;
- local services that have developed peer-led approaches and projects as part of their overall provision, including providing ex-drug users with the opportunity to take on roles such as volunteers and mentors.

## 2. Methods Employed

The information gathering process undertaken by UCLAN for this practice guide is outlined below.

### Phase 1

A questionnaire was sent to all 149 DAAT areas and a consultation exercise was carried out with a range of community groups to gain an understanding of the number and range of existing peer-led projects across England.

DAAT partnerships were asked to report on all peer-led initiatives they were aware of in their area, whether commissioned by them or not, and including any from relevant associated sectors such as the mental health and HIV sectors. DAAT partnerships were also asked to report on any specific action they had taken in developing or attempting to develop peer-led support to meet locally defined diverse needs. A consultation process was also undertaken with some of the community groups involved in the Department of Health's Community Engagement Programme.

Of 149 questionnaires that were sent out to DAAT partnership in July 2005, 82 were returned by September 2005. A total of 164 peer-led projects were identified and 24 of these were selected for inclusion in Phase 2. The selection was based on ensuring that there was a diverse range of peer-led projects, wide regional representation and projects that focused on issues other than drugs in order to learn from the experiences of other sectors.

### Phase 2

Key individuals from all 24 projects listed below<sup>3</sup> were interviewed:

#### North East:

- **PANIC** – Peer-led support for parents, carers and families of drug users
- **ADVANCE** – Peer-led support for ex-users and ex-offenders with attention deficit hyperactivity disorder
- **PINS** – Peer-led support project for parents and carers of drug users
- **Hart Gables** – Peer-led support for lesbian, gay, bisexual and transgender (LGBT) people
- **Durham University LGBT Group**

#### North West:

- **Park View** – 12-step residential programme with peer-led element
- **STASH** – Non-abstinence-based peer-led support

#### Yorkshire and Humberside:

- **Making it Clean** – Five peer-led support projects including one focused on parental drug users

#### East Midlands:

- **BAC-IN** – Peer-led support project for ex-users from black and minority ethnic communities
- **Livin-It** – Peer-led support project for women and carers
- **Project Recruit** – Return-to-work project for drug users

<sup>3</sup> All projects have given their permission to be identified.

- **OASIS** – Peer-led support project for parents and carers
- **Zacchaeus Project** – Faith-based support scheme

#### London:

- **NAFAS** – Abstinence-based peer-led support for ex-users from black and minority ethnic communities
- **OPAM** – Peer-led support for black African HIV-positive men
- **BUBIC** – Open-access peer-led support project which recruits a large number of black crack users
- **St Giles Trust** – Peer-led support for prisoners and ex-prisoners
- **i-base** – Activist-led specialised information support service on HIV treatment

#### South East:

- **ASIAN** – Peer-led support for Pakistani ex-prisoners
- **OUT** – Oxfordshire User Team

#### South West:

- **Vita Nova** – Abstinence-based peer-led support project using theatre and arts
- **The Club House** – Peer-led support group including groups for parents and carers and ex-prisoners

#### West Midlands:

- **SWISH** – Sexual health support service for women involved in sex work, including peer support
- **RAMA** – Mental health peer-led support for black and minority ethnic populations

## Phase 3

One-to-one interviews were conducted with thirty stakeholders from the substance misuse treatment system. The stakeholders were made up of national, regional and local representatives from a variety of organisations identified as having individuals with expertise on, or insight into, peer-led support issues.

### 3. Key Themes

Key themes that have emerged from this work suggest that DAAT partnerships should not view the commissioning of peer-led support just as the purchasing of a new service or intervention. It may involve the DAAT partnership developing new supportive commissioning practices that provide practical support for existing peer-led approaches, alongside commissioning or enhancing existing provision and/or developing new provision. Indeed, effective commissioning will require a commitment to innovation, a flexible approach, a certain level of risk management and an acceptance that sometimes peer-led projects and approaches will require intensive support and direction. It may also require working with other DAATs and regional partners to support peer-led provision that works across a number of DAAT boundaries.

DAAT partnerships should be aware that peer-led approaches may already have been established locally by ex-users and that they could require assistance to be maintained or to be developed further. DAAT partnerships need to consider the most appropriate way of supporting these approaches and projects without losing the initiative, drive and enthusiasm of the ex-users or the local community groups that developed them.

Several DAAT partnerships contributing to this practice guide are already successfully supporting and commissioning a range of peer-led approaches by:

- working alongside established self-help networks;
- supporting existing peer-led projects and approaches;

- helping existing peer-led projects and approaches to adapt to meet newly identified diverse needs; and
- supporting the development of new peer-led projects and approaches that target specific groups.

Both the DAAT partnerships and the projects contributing to this practice guide maintain that if sustainable peer-led approaches are to be available at local levels an equal balance of peer involvement and professional and organisational involvement is required. The common key themes emphasised by the contributors of this practice guide are:

- appropriate assessment of local aftercare needs is required to inform commissioning of new and existing peer-led approaches;
- providing drug users with choice and access to different peer-led approaches;
- developing and supporting local peer-led champions;
- providing assistance to peer-led projects and approaches with funding and resources;
- establishing proportionate monitoring systems for peer-led projects and approaches;
- helping peer-led projects and approaches to develop support systems and networks.

These key themes are discussed in detail below, and should also be considered in conjunction with the project examples in Section Two, which provides an overview of how specific projects have overcome problems and barriers in relation to these key themes.

### 3.1 Assessment of local aftercare needs to commission peer-led approaches

The aftercare needs of diverse communities will vary significantly in different areas of England. Although there are some common issues for specific groups, such as black and minority ethnic communities or lesbian, gay, bisexual, and transgender communities, these populations themselves are diverse and their needs differ by geographical area and by context. For example, in rural communities, developing or accessing existing peer-led support can be difficult because of a lack of public transport and suitable childcare. These issues can be further complicated by high levels of stigma for some groups around drug use and the difficulties of maintaining anonymity.

Therefore DAAT partnerships need to consider:

- what peer-led approaches and projects are currently available in their local area;
- who currently accesses peer-led support, when and how;
- what local diverse needs are not being met by existing peer-led approaches;
- how local diverse needs could be met through enhancing existing peer-led approaches;
- how local diverse needs could be met through facilitating or commissioning new peer-led approaches.

#### What peer-led approaches and projects are currently available

The information gathered for this practice guide suggests that a number of small

peer-led projects and approaches have developed organically and are unknown to DAAT partnerships and the substance misuse treatment system. Equally, many of these peer-led approaches and projects are unaware of the existence of DAAT partnerships or the potential help and support that the DAAT can provide. This is particularly the case for groups, such as those from black and minority ethnic communities, who historically have been unaware of drug services, or women with children who are apprehensive of approaching services because they fear the intervention of statutory services where their children are concerned.

An assessment of which groups of users are currently accessing peer-led provision can be made by devising a simple monitoring system, which can be compared against the treatment population and general population data. This could be developed with local user groups, and could build on the existing local evidence base of what is offered, to whom, where and when in the treatment journey. The National Treatment Agency's Diversity Assessment Package ([www.nta.nhs.uk/news/050929A.htm](http://www.nta.nhs.uk/news/050929A.htm)) has useful guidelines and case studies on developing general basic systems for collecting, analysing and monitoring data for diverse groups.

#### Who accesses peer support, when and how

Drug users access peer-led support at various stages of their treatment journeys and for different reasons. For example, for some drug users peer-led support can begin the process of contemplation that leads to engaging with treatment services. Therefore it is essential that the idea of peer-led approaches and support is introduced

to drug users as early in their treatment journey as possible, as the case example below demonstrates.

### CASE EXAMPLE

**Name:** Janine

**Gender:** female

**Age:** 26

**Ethnicity:** white British

**Key quote:** *'Ex-users are there for you to get through the hard times. They know what's going on and tell it as it is. I can look up to people who have got off and stayed straight.'*

**Background:** Janine started using heroin and crack at the age of 15 while still in local authority care. She moved in with a dealer when she was 16. She was involved in sex work for six years and served a number of prison sentences for shoplifting.

**Type of support accessed:** peer support, social network, advocacy and education

**Individual outcomes:** Support from peers encouraged Janine into treatment services and education. Now on a methadone script, she is only using drugs occasionally. Her confidence and self-esteem has increased. She has started to take pride in her appearance and has engaged in hairdressing, arts and sports activities.

Other drug users may make contact with or be referred to a peer-led project at the end of their treatment programme, or on leaving prison. The case example below highlights the importance of encouraging treatment providers to work alongside peer-led projects and approaches to jointly support drug users.

### CASE EXAMPLE

**Name:** Tess

**Gender:** female

**Age:** not given

**Ethnicity:** not given

**Background:** Tess used heroin for over twelve years. She had spent long periods of time in prison, but always started using drugs again on release. She was a chaotic user who suffered a number of related health problems, including deep vein thrombosis and hepatitis C. She was eventually admitted into hospital weighing six stone and with severe blood clots. After spending several months in hospital, she began to recover and realised she needed help and support.

**Type of support accessed:** social support, peer mentoring, advocacy

**Individual outcomes:** Tess completed a twelve-month rehabilitation programme. While at the service she was introduced to a families peer-led project. Tess has now been a member of the project for over two years, lives with her partner and son, has a full-time job and is enjoying a stable lifestyle.

Some ex-users will not want to access a peer-led project but will still require occasional support. Several contributors to this practice guide highlighted that some families and carers prefer approaches that use the telephone or one-to-one support rather than those that are group-focused. Some ex-users simply want one-to-one peer-led support at times or in situations in which they may feel vulnerable. The quotation below highlights the experience of an ex-user who provided one-to-one peer support:

*'I was asked by the service and by Adam to go with him to cash his giro cheque at the local post office, as he did not want to bump into his old gang on his own, and in particular a specific individual. Adam was concerned that he may get bullied into handing over his money, or may feel weak himself and end up scoring drugs. I agreed to support him and we did bump into this group. We were able to walk straight past and carry on with our day. Adam reported that the experience gave him a lot of self-esteem and I felt it contributed to his continued abstinence.'*

### What local needs are not being met by existing peer-led approaches

Understanding what diverse needs are not being met by existing peer-led provision and what approaches can fit into the context of local aftercare services can be informed by user and carer involvement and consultation to establish needs and priorities.

The NTA emphasised that the engagement of drug users in all aspects of their treatment, through involvement in their care plan, is central to the delivery of effective services and aftercare provision. This view is supported by both DIP and the National Offender Management Service (NOMS). DAAT partnerships need to demonstrate a commitment towards greater user and carer involvement that fully includes them in the development of local drug treatment planning processes, including the establishment of priorities to reflect diverse needs.

However, some DAAT partnerships struggle to develop any kind of meaningful and sustainable consultation

or partnership with users and carers. As a minimum, DAAT partnerships should support the establishment of consultation groups to enable ex-users who have completed treatment to discuss their current and ongoing needs. Drug users in treatment could also be asked during the development of their care plans what aftercare they may need and whether they would want opportunities to assist in any self-help activity. This is particularly important as some users may not understand the value of aftercare provision, specifically peer-led support, so these discussions at an early stage may be helpful to users.

Some DAAT partnerships have developed user involvement posts to take a lead role on taking forward user and carer involvement and consultation programmes. There are also an increasing number of training courses looking at improving user involvement that aim to support the development of networks between those responsible for developing strategies and those responsible for implementation, including ex-users.

### How local diverse needs can be met through enhancing existing peer-led approaches

A number of peer-led projects are already being supported by, and working closely with, DAAT partnerships. These established peer-led projects can often meet newly identified diverse needs by changing aspects of the support that they provide or by developing additional models or modes of support. As the project profile below demonstrates, STASH, which has peer-support elements as part of its provision, has revisited its aims, purpose and approaches to enhance its existing peer-led support work.

## PROJECT PROFILE: STASH

**Area:** Salford

**Peer-led element:** professional and peer collaboration

**When:** all stages of the treatment journey

**What gap does it fill?** STASH provides structured day care, including care for those in early recovery, and also accepts criminal justice referrals. Though STASH is not exclusively a peer-led service or a service for female drug users, it has actively developed peer-led support targeting this group.

**Development:** It was established in 2004 and is funded by Salford DAAT. It was originally set up to deliver an outreach programme, e.g. with clients on probation.

**Main activities:** The structured day programme enables people in recovery to access support, engage in activities and gain confidence, skills and qualifications as part of their move-on journey. Members put ideas for activities forward, but the focus is on inclusion and involvement, not merely attendance. STASH has a diverse membership in terms of gender, ethnicity and sexuality. It employs a full-time women's development worker funded by the DAAT to address the needs of female drug users who have specific difficulties accessing support. The volunteer programme and peer development project offers people access to training, and also provides

the opportunity to facilitate groups. Some people who have a criminal record have been able to complete the volunteer programme and get Criminal Records Bureau clearance.

## How local diverse needs can be met through commissioning new peer-led approaches

Some DAAT partnerships, and their local stakeholders within the substance misuse treatment system, have identified the need to develop and commission new peer-led approaches targeting specific groups, particularly where existing forms of peer-led support cannot be enhanced to meet these needs. Innovative approaches to establish need and provision should be considered, as highlighted by the example below.

### ASIAN

This is a peer-led project developed for ex-users, prisoners and ex-prisoners from the Pakistani community. Through ethnic monitoring data, Reading DIP identified that large numbers of Pakistani men were refusing treatment despite testing positive for drugs at the point of charge. These men were also not engaging with mainstream services. A needs assessment was undertaken using a community engagement model that was supported by UCLAN, Reading User Forum and Reading DIP. Prisoners were recruited and trained to undertake the research. As a result, prisoners and ex-prisoners from the Pakistani community formed a peer support group, which now supports Pakistani prisoners in prison and on release.

## 3.2 Providing choice and access to different peer-led approaches

No single model or approach is ideal for all users. A number of peer-led approaches are small and straightforward, and while some may disband once they have achieved their goals for the participants, others may develop further as projects in their own right or as part of other projects or community groups. Some focus on abstinence, while others choose not to. The NTA highlights that any treatment approach in line with *Models of Care: Update* (NTA 2006) should be well integrated into systems of care and social support<sup>4</sup>.

The idea of using more than one approach or model is supported within other sectors, such as the mental health sector and in working with prisoners. For example, the HM Prison Service document *Good Practice Guide for Peer Support Schemes* emphasises that in some establishments there are significant benefits from, and scope for, running more than one type of peer-led scheme.

DAAT partnerships should aim, where possible, to encourage innovation and the development of a range of different approaches to facilitate choice for users. Whether supporting existing peer-led approaches or commissioning new ones, they should consider:

- working alongside established self-help networks;
- helping existing peer-led projects and approaches to adapt to meet newly identified diverse needs; and

- supporting the development of new peer-led projects and approaches that target specific groups.

### Working alongside established self-help networks

DAAT partnerships should recognise the valuable support that is provided by established self-help networks such as Alcoholics Anonymous (AA) and Narcotics Anonymous (NA). AA and NA have proved to be effective and popular, although their methods and approaches will not suit all drug and alcohol users. The 'self-help' model allows diverse needs to be identified by users themselves, and consequently there are gay and lesbian NA and AA groups, foreign-language groups, and so forth. Individuals are able to attend the groups they feel best meet their needs.

#### Narcotics Anonymous (NA)

NA's aim is to provide an environment in which drug users can help one another stop using drugs and find a new way to live. NA's recovery process and support network are linked together. Members share their successes and challenges in overcoming addiction and living drug-free lives through the principles in the '12 Steps' and '12 Traditions of NA', which are core to NA's recovery program. As a fellowship, NA does not employ professional counsellors or provide treatment centres. There are no social, religious, economic, racial, ethnic, national, gender or class-

<sup>4</sup> *Retaining clients in drug treatment: a guide for providers and commissioners* (June 2005), NHS National Treatment Agency for Substance Misuse.

status membership restrictions. There are no fees for membership: while most members regularly contribute small sums to help cover the expenses of meetings, such contributions are not mandatory.

Contributors suggest that some individuals who are active members of peer-led projects also attend NA or AA meetings. This is the case for some drug users at Park View. Park View, which is outlined below, is not exclusively a peer-support project, but does have peer-support elements as part of its provision.

### PROJECT PROFILE: Park View

**Area:** Liverpool

**Peer-led element:** professional and peer (self-help groups) collaboration

**When:** after detoxification or on release from prison

**What gap does it fill?** Park View provides residential rehabilitation services to local people who may have problems in accessing safe accommodation when they come out of prison or leave detoxification services.

**Development:** The service was established in 2003. The peer stakeholder who set up Park View is in recovery himself. He bought the house with his own funds and got in touch with the local DAAT and the Probation Service to help develop the project.

**Main activities:** Park View aims to introduce people to the fellowships (NA or AA). There is a strong focus on group work. People typically stay for three months in a primary group and three months in secondary group. This helps people move toward independence. Later, people are encouraged to engage in education, training, and voluntary and paid work. Park View runs a family group once a week, and engages in family work, particularly where parents have dependent children. Diverse needs are also managed individually: for example, some members have been excused from group sessions to attend the local mosque.

### Helping existing peer-led projects to adapt to meet newly identified diverse needs

The information gathered for this practice guide indicates that a number of peer-led projects are already being supported by, and working closely with, DAAT partnerships. These established peer-led projects can often meet newly identified diverse needs by changing aspects of the support that they provide or by developing additional models or modes of support. For example i-base, outlined below, has adapted its provision in response to newly identified local needs.

### i-base

This is a peer-led project that provides technical information and advocacy on all aspects of HIV, including treatment, to HIV-positive populations and clinicians. There has been a large increase in HIV among the heterosexual population and in the African population, particularly women. i-base has responded to these changes by producing information on pregnancy and infertility for those with HIV in different languages.

PINS employs a full-time project manager, a support and advice worker, and nine volunteers.

**Main activities:** PINS offers practical and emotional support, befriending, mentoring, drop-in facilities, drug awareness, aftercare support training courses, parenting skills courses and advice throughout Hartlepool. PINS has developed a working partnership with two young people's counselling and mentoring services to enhance 'fast-track referrals'.

## Supporting the development of new peer-led approaches and projects that target specific groups

Some DAAT partnerships have identified the need to develop and commission new peer-led approaches targeting specific groups, particularly where existing forms of peer-led support cannot meet these needs and new innovative approaches need to be considered. Needs have also been addressed by local champions. The following example highlights the establishment of a peer-led project for parents and carers.

### PROJECT PROFILE: Parents in Need of Support (PINS)

**Area:** Hartlepool

**What gap does it fill?** The organisation provides support, advice and information to parents and carers of people involved in drug use.

**Development:** PINS was established in October 1996 by two parents who were unable to find an agency that provided support to parents and carers.

Some peer-led support projects and approaches have also begun using information technology as an innovative way of enabling people to access support. Two examples are outlined below:

- **Narcotics Anonymous (NA):** NA has recently developed its first online forum to support drug users who have difficulty attending NA meetings.
- **Lesbian, gay, bisexual and transgender (LGBT) populations:** some LGBT groups have developed email discussion lists which provide a useful way of maintaining links and offering support across dispersed or isolated populations. People can have email forwarded to their personal email addresses or can access a central message board. Online forums also offer useful ways of exchanging ideas and information, and developing and maintaining friendships.

### 3.3 Supporting and developing local champions

The actions of key individuals with an interest in or commitment to a target group, whether within a DAAT, from the substance misuse treatment system or from the wider community, are often integral to identifying diverse needs and supporting the development of appropriate peer-led support in diverse communities. Contributors agree that the development of peer-led projects at local levels requires an equal balance of ex-user catalysts and champions and professional champions.

#### Ex-users as catalysts and champions of peer-led support and projects

Many of the peer-led projects and approaches outlined in this practice guide were initiated by an individual ex-user or a group of ex-users who had identified unmet needs in their community. These individuals were not only the catalysts or instigators of these projects, but also their champions. They had a crucial role in creating the ideas and focus of the project: why it was needed, whom it was for and what support it should provide. They also played a role in the daily running of the project and the ongoing delivery of support.

#### Professional champions

There is no doubt that ex-users have a crucial role to play in the setting up of peer-led projects and approaches. Many projects also need external support from a local drug agency or the DAAT

partnership to access resources, make the project happen and provide assistance to ensure its ongoing development. The action most commonly reported by DAAT partnerships in developing peer-led support is the appointment of a specific post or part of a post to coordinate the development of this area of activity.

#### BUBIC (Bringing Unity Back in the Community)

A black Caribbean professional stakeholder from the substance misuse treatment system was instrumental in the development of BUBIC, a peer-led project which grew out of the needs of black and minority ethnic crack users. Using his knowledge, skills and experiences of local services, he helped BUBIC to identify a venue, access initial funds to pay for rent, refreshments and literature to promote the project, linked them with local partners and appointed a steering group to support the continued development of the project. He provided ongoing support and supervision, helping the ex-users to develop their capacity to deliver the support by themselves. He also helped identify a relevant host organisation, the North London Partnership Consortium, whose remit was to help small organisations to develop. BUBIC received funds and help with managing the project's finances, accessing other community initiatives (e.g. urban regeneration) and creating consistent systems and structures to manage the work.

### Making it Clean (MIC) groups

When MIC in Sheffield wanted to develop peer-led support for drug-using parents, they approached a worker in Sure Start who was already running parenting courses and had the necessary skills and expertise. The MIC for Parents group developed as a partnership between Sure Start and MIC. This had the additional advantage of making available resources for childcare, which supported attendance to the group.

## 3.4 Assistance with funding and resources

Ex-user champions use very different funding strategies to set up and support their peer-led projects and approaches, including:

- fund-raising (e.g. organising dances and events);
- one-off grants from interested businesses, individuals or charitable organisations;
- small grants from social services' drug and alcohol teams;
- non-financial support from DAATs or treatment providers, such as a venue for meetings and office space.

Many peer-led projects do not have the resources of large statutory or voluntary organisations, and often depend on volunteers and goodwill. The strategies used to raise funds may allow ex-user

champions to set up their projects, but often this is not sufficient to ensure regular income for their ongoing development. Ex-user champions also face the challenge of dealing with bureaucracy, conditions of funding, and in some cases achieving charitable status.

DAAT partnerships need to assist peer-led projects to identify funding sources, and to help individuals and projects to understand how to access one-off or sustained funding. They can help projects to meet funding conditions and requirements by means of:

- small one-off amounts of funding from a range of sources;
- small amounts of regular grant funding;
- hands-on support in the development of policies and procedures, writing of funding bids, development of monitoring systems and so forth;
- funding for facilitators, administrators or other posts;
- development of a post with specific responsibility to help initiate and support peer-led projects.

There is a risk that DAAT partnerships may view peer-led provision as low-cost service providers and could fund them at the expense of other aftercare provision or agencies from the substance misuse treatment system. DAAT partnership must view peer-led approaches as part of a continuum of treatment and care in their local area, which should be funded to complement the work of professional substance misuse services.

### 3.5 Proportionate monitoring

The Voluntary Sector Compact Guidance<sup>5</sup> states that the monitoring of services should be proportionate and should not overburden agencies. For example, wherever possible monitoring requirements should be joined up to match those of other funders, so as to reduce the bureaucratic burden on the delivery agency or project.

Proportionate monitoring is particularly vital for peer-led approaches and projects. While it is the duty of funding bodies to ensure the accountability and performance of the projects or services that they fund, peer-led projects often will not have the skills and resources to meet these requirements.

DAAT partnerships should, where possible, restrict the bureaucratic burdens they place on peer-led projects, allowing them the freedom to focus on the agendas that brought them together. DAAT partnerships should also consider proportionality of monitoring requirements against the level of funding being made available.

DAAT partnerships should consider providing administrative support and assistance with reporting requirements, especially for newly established projects and approaches. For example, finding a suitable host organisation from the substance misuse treatment system that is able to receive funds and make necessary payments on behalf of a peer-led project will assist in removing some of the administrative burdens. DAAT partnership should also ensure that:

- simple contract monitoring, conditions of funding and performance management systems that are transparent and accessible are jointly agreed with peer-led projects;
- realistic timescales for reporting, that take into account the limited resources of peer-led projects, are in place;
- where appropriate, financial arrangements or agreements should be in place with other DAAT areas, to allow people to access peer-led support and approaches that may not be available locally.

### 3.6 Developing support systems and networks

Contributors suggest that in order to sustain peer-led projects and approaches, DAAT partnerships should consider developing systems to provide support to the ex-user peers who deliver the support. This can include providing supervision, access to training, or mentoring and guidance to ex-users. This will help ex-users to build their self-esteem, confidence and personal growth, and to understand and set appropriate boundaries and avoid, for example, role confusion, over-identification, or 'getting in too deep' within their projects.

The following example outlines how some of these issues were addressed by Livin-It with support of their local DAAT.

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<sup>5</sup> NTA and Home Office guidance for commissioning drug treatment services from voluntary and community sector organisations, based on the principles of the Home Office Voluntary Sector Compact (2005).

## PROJECT PROFILE: Livin-It

**Area:** Nottinghamshire

**What gap does it fill?** user and carer advocacy service, family and carer projects and a specialist project for grandparent advocacy

**Development:** it was established in 2004 with funding from the DAAT, and hosted through the Primary Care Trust (PCT) with the aim of developing user and carer peer-led involvement and mentoring. The project became part of the local treatment/aftercare planning user and carer involvement strategy. Two peers were recruited on salaried positions by the DAAT. They were given time to shadow other workers and explore the approaches of other organisations. The project appointed a steering group and the two peers were provided with supervision, mentoring and support in developing a plan for the project. This support was important for these peers in managing their transition back into full-time paid employment.

**Main activities:** Livin-It provides one-to-one mentoring forums across a large rural area, which includes seven different boroughs and district councils, one-to-one peer support for people in treatment services, including those on the Criminal Justice Integrated Team (CJIT) caseload, and support for parents and carers of substance-using children. After two years it has own premises, and is integrated with other community partnership agencies, from which it receives individual and team mentoring. Livin-It recently won an annual Primary Care Trust award in recognition of its peer support and patient advocacy elements.

A number of the peer-led projects contributing to this practice guide were keen to develop links with other projects they saw as facing similar challenges to themselves. Developing links and networking with other peer-led projects offered them the opportunity to seek advice, information and advocacy, and to gain access to training opportunities. DAAT partnerships, along with regional partners, should consider supporting and promoting the development of local and regional links and networks. These support systems can also help projects increase the range of peer-led support and approaches that they provide, and assist a more diverse range of users, as demonstrated by the example of Club House below.

## Club House

Club House is an independent organisation run by a combination of users, ex-users and professionals delivering aftercare support. It offers a range of education, training and employment opportunities and works closely with the local college, the Learning and Skills Council and local employers. The DAAT coordinator encouraged a key individual to attend an accredited training course about supporting families and communities. This led to the development of a peer-led education course and support group around parenting skills. The training also provided capacity building for the individual, who gained a qualification, and helped to develop a strand of support for parents, who were previously an under-represented group.

Some ex-users delivering peer-led projects also suggested that they had benefited from attending relevant local and national conferences. These events had given credibility to the services they delivered within their peer-led projects and had helped ex-users to develop and increase their confidence and knowledge.

Examples of individuals using peer-led support as a platform from which to work towards personal goals and gain work experience are highlighted in the following profile of Oxfordshire User Team.

### PROJECT PROFILE: Oxfordshire User Team (OUT)

**Area:** Oxfordshire

**Peer-led element:** professional and peer collaboration

**When:** all stages of the treatment journey

**What gap does it fill?** This is a self-help organisation promoting social inclusion and providing opportunities for people overcoming drug and alcohol problems.

**Development:** It was established in 2002 and grew out of peer education sessions. The team has two full-time staff and eight volunteers, and receives ongoing support from Oxfordshire DAAT's User Involvement Co-ordinator.

**Main activities:** OUT organises peer education workshops (identified as a model of good practice by the NTA), peer advocacy, peer support, and research projects (including a project on criminal justice). Volunteers are made up of current and ex-drug users, who are encouraged to take on roles in the group and trained to deliver support and services. This allows volunteers to work towards personal goals and gain work experience. They receive a minimum six-month work placement and are encouraged to move on to full-time work or education when ready.

# 1. Examples of diverse approaches to peer-led support

One of the aims of this practice guide is to promote practice and innovation. This section presents examples of peer-led approaches that illustrate the variety of ways in which peer-led support can be delivered to specific populations and groups to meet their diverse needs. The examples are of peer-led approaches from within the substance misuse sector and other sectors, and focus on:

- common barriers and problems faced;
- how to develop peer-led support;
- case profiles that outline examples of peer-led approaches; and
- case examples of people who have accessed this form of support.

These examples should not be seen as preferred models, although many of them are examples of practice that DAAT partnerships and commissioners may be able to build upon. The examples presented cover the following groups:

- female drug users;
- female sex workers;
- black and minority ethnic populations;
- faith communities;
- parents and carers;
- people living in rural areas;
- prisoners and ex-prisoners.

In addition, three examples are provided from outside the substance misuse sector to highlight cases of transferable practice:

- lesbian, gay, bisexual and transgender (LGBT) populations;

- people with mental health problems;
- HIV-positive populations.

## 1.1 Female drug users

### Common barriers:

- 1) **Stigma and isolation:** Women, including women with children, may feel that they are more likely to be stigmatised for their drug use and fear the intervention of statutory services where their children are concerned. Although this may not be the case, a lack of information and knowledge about available support means that they might be reluctant to get involved in services or groups within their local communities. The result is that they could become isolated, which may lead to relapse or exacerbate their drug misuse.
- 2) **Childcare responsibilities:** A number of contributors to this practice guide have indicated that many drug-using women have difficulty in accessing any type of support due to their childcare responsibilities. Women are more likely than men to have dependent children or other caring responsibilities<sup>6</sup>. For drug-using women the high costs of appropriate childcare are likely to prevent them from accessing services or groups without crèche facilities. Even where such facilities exist, if the women live in areas with poor transport links they may find it difficult to transport themselves and their children to the service or project.
- 3) **Lack of gender-specific support:** Some drug-using women have been in violent and abusive relationships

<sup>6</sup> Klee, H., Jackson, M., and Lewis, S. (2002) *Drug Misuse and Motherhood*, Routledge: London.

with men. They may find it difficult to seek support in mixed-gender groups as they may feel unsafe and unable to talk openly about such issues.

### Developing peer-led approaches for female drug users:

- 4) **Importance and development of professional champions:** Some DAATs have appointed specific posts to work with drug-using women. Such posts can help to initiate, develop and champion peer-led approaches. For example, in the case of STASH, a service based in Salford, the DAAT partnership created a specific post to carry out a needs assessment of local drug-using women. This resulted in a support programme for women that focused on reducing their isolation through the development of informal networks. This enabled the local women to support each other.
- 5) **Development of women-only groups:** Women-only peer-led support groups can encourage women, including those with children, to find support and friendship from other women within their local community that can help to reduce their feelings of isolation.
- 6) **Funding for childcare and transport:** DAAT partnerships may consider providing funding to appropriate peer-led projects and groups to cover some childcare and transport costs for women with children. For example, Making it Clean for Families was allocated funding to support childcare and transport costs as this was identified as being essential to allow women to have the opportunity to attend.

### PROJECT PROFILE: Making it Clean (MIC) for Families

**Area:** Sheffield

**Peer-led element:** professional-led with peer support elements

**When:** all stages of drug-using career

**What gap does it fill?** Although MIC is not solely for women, the vast majority of those who access support are female drug users with dependent children.

**Development:** MIC was established in October 2000. A DAAT user involvement worker and five users originally set it up to support people at all stages of the treatment journey. MIC-4 Families was set up as a partnership between MIC and the Sure Start programme, which offers parenting courses and parenting support services for children under 5. However, there was a lot of resistance from parents using Sure Start about drug-using parents also attending these courses. The drug-using parents wanted to meet around issues specific to their needs. Sure Start workers, drug treatment providers and health visitors eventually found a venue for this group.

**Main activities:** The project provides transport for parents to attend groups, provides a crèche facility, and operates a mixture of social and leisure activities, e.g. swimming and bowling, and courses and discussions.

## 7) Innovative and flexible approaches:

Given the concerns of many drug-using women with children around stigmatisation and the possible involvement of statutory services where their children are concerned, some women find it easier to access telephone or outreach support. DAAT partnerships might consider such options as useful alternatives to group-based peer-led support.

### CASE EXAMPLE

**Name:** Karen

**Gender:** female

**Age:** 39

**Ethnicity:** white British

**Project:** The Club House

**Key quote:** *'This prompted me to take a look back over the last three years and see just how much has changed in my life over that time.'*

**Background:** Karen is an ex-prisoner who came to the project from prison having lost her home and family. She had been battling with heroin and crack problems for over 25 years. She had no idea what direction to take in her life, except that she did not want to go back to prison.

**Type of support accessed:** Karen initially took part in yoga and tai chi classes and found them to be beneficial. She also completed the 'Steps to Excellence' self-awareness course. She was reunited with her children and able to take them on outings organised by the Club House.

She signed up at a college to study for a diploma in anatomy and physiology with a view to becoming a reflexologist. By the end of the first year, she had become a volunteer at the Club House. She moved on to the Foundation Programme, which works with clients who are active and problematic drug users.

**Individual outcomes:** Today she is a confident professional sessional worker at the Club House 'Future Project', which offers peer support to clients from the criminal justice system in aftercare. Karen is working towards a full-time post and is now enjoying her life.

## 1.2 Female sex workers

Only one example of peer-led support for sex workers could be found for this practice guide, SWISH (Sex Workers Into Sexual Health). This is for female sex workers and is not entirely peer-led but operates as a peer-professional collaboration.

### PROJECT PROFILE: SWISH (Sex Workers Into Sexual Health)

**Area:** Coventry

**Peer-led element:** professional-led with peer support elements

**When:** all stages of sex work careers

**What gap does it fill?** There has been a street sex working area in Coventry for more than 30 years and SWISH has provided targeted provision aimed at this group.

**Development:** In 1998 a women's health specialist employed by the Terence Higgins Trust began to look at the needs of local female sex workers and started a six-month pilot project. The project started with a £2,000 grant from the Primary Care Trust to allow four volunteers to give out sexual health resources and hot drinks to women sex workers on the street. The project worked closely with the police to ensure the safety of the volunteers.

**Main activities:** In 2002 a grant of £55,000 was secured from Communities Against Drugs and Building Safer Communities. This paid for a full-time post for two years to undertake arrest referral and court support work. In 2004, the DAAT partnership and Building Safer Communities made a £68,000 grant and the project began to develop peer champions, who are also able to carry out outreach work in massage parlours. Other activities include ensuring that sex workers have access to hepatitis B vaccinations. SWISH has used national networks such as the National Sex Workers Forum to draw on models of best practice.

### Common barriers:

- 1) **Impact of drug use:** Up to 90% of female sex workers are dependent on drugs (Hester and Westmarland (2004), Cusick, Martin and May (2003)). Contributors from SWISH believe that sex work and drug use (particularly crack) can operate as mutually reinforcing activities, and that sex workers who use drugs can

be more chaotic and therefore more difficult to engage into treatment or aftercare provision.

- 2) **Lack of flexible support and approaches:** Sex workers may not be able to access support at times and in ways that drug users can. Sex workers working in isolation or in small numbers, who work in more dispersed rural communities, indoors or at unsocial hours, may find it more difficult to access traditional forms of support.
- 3) **Support from DAT partnerships and commissioners:** Contributors highlighted the difficulties they had in obtaining the support of DAAT partnerships and commissioners, particularly in developing peer-led approaches for sex-workers in rural areas. The reason for this appeared to be that as the majority of women were working indoors there was no visible sex work scene and no complaints from the local community, so there did not appear to be any issues to address.

### Developing peer-led approaches for sex workers:

- 4) **Importance and development of professional champions:** Contributors from SWISH have emphasised that professional champions have been key to the development of peer support for female sex workers. SWISH operates as a peer-professional collaboration in which the main aspects of the running of the scheme are managed and operated by professional staff, so unnecessary burdens are not placed on peer champions.

- 5) **Importance and development of peer champions:** The professional champions at SWISH have developed peer champions from among the sex workers by building relationships with the women sex workers over a prolonged period and identifying and supporting individuals willing to take on the role of peer champions. Contributors believe that peer champions are a fundamental aspect of successful outreach work with sex workers because peers are trusted and can help to build sustainable relationships.
- 6) **Establishing flexible support and approaches:** A variety of flexible approaches need to be considered if the needs of sex workers are to be met. For women working outdoors these may involve developing peer-led outreach approaches in the sex working area. For women working indoors it may involve building relationships with proprietors of sex work venues over a sustained period to allow peer champions to work with these particular sex workers. SWISH suggested that one way of developing relationships with the proprietors of sex work venues is to telephone massage parlours listed in the Yellow Pages and request a meeting with them in a neutral venue to outline the work and support provided by the peer champions.

The chaotic lives of some drug-using sex workers mean that making sustained lifestyle changes can be difficult. Therefore, any approach needs to be delivered at the pace of each individual.

## CASE EXAMPLE

**Name:** Lucy

**Gender:** female

**Age:** 22

**Ethnicity:** South Asian

**Project:** SWISH

**Background:** Lucy had had a heroin and crack problem since the age of 13. She left her family home at 15 and started to sell sex to buy drugs. Lucy was homeless, either sleeping in shop doorways or in crack houses and often in very vulnerable situations. She experienced violence and was raped on many occasions.

**Type of support accessed:** social and telephone support, peer mentoring and advocacy.

**Individual outcomes:** Lucy has now returned to her family home after five years of sleeping rough and using heroin and crack. The turning point for Lucy was the last time she was raped, when she was also very badly beaten. Lucy was unaware that she was expecting a baby and this attack was partly responsible for her miscarriage. Lucy has not used drugs since her return home and continues to use telephone support.

## CASE EXAMPLE

**Name:** Susan

**Gender:** female

**Age:** 35

**Ethnicity:** mixed parentage  
(Caribbean and white British)

**Project:** SWISH

**Background:** Susan used heroin for twelve years and crack for six years. Within the first year of her heroin use she lost her home and her daughter, who is cared for by her mother. Susan slept rough for many years and led a very chaotic lifestyle. She spent many years in and out of prison, mainly for petty offences. However, each time she was released Susan would go back to selling sex and using drugs.

**Type of support accessed:** social support, peer mentoring, advocacy.

**Individual outcomes:** Susan spent considerable time in a rehabilitation centre. She is now drug-free, in a stable relationship, and is building a relationship with her daughter. This is a long, slow process for both of them but they are making good progress. Susan has been drug-free for twelve months but still seeks support by means of telephone.

experiences about culture, family and discrimination, as the example below from an individual user highlights:

*'I was in this group and I was talking about my drug use, and also about my family and religion and all of the pressures I felt from these different places. When I looked up, everyone else is looking at me like, what's this guy on about?'*

## Developing peer-led approaches for black and minority ethnic populations

- 2) **Importance and development of professional champions:** DAAT partnerships can consider establishing new peer-led groups and approaches for black and minority ethnic communities. While this will be necessary in some circumstances, DAAT partnerships should also consider what changes can be made to existing forms of support to make them more inclusive.

Professional champions with an interest in and commitment to a group of users have been vital to the development and sustainability of BAC-IN. This project provides an identity and a sense of belonging to individuals from black and Asian cultures, and is outlined below.

## 1.3 Black and minority ethnic populations

### Common barriers:

- 1) **Being a minority in a peer-led support group:** Some black and minority ethnic drug users can feel uncomfortable in peer-led groups where the majority of people are from different cultures to theirs. They might be unable to share issues and

### PROJECT PROFILE: BAC-IN (Black and Asian Cultural Identification of Narcotics)

**Area:** Nottingham (County and City)

**Peer-led element:** entirely peer-led

**When:** all stages of the treatment journey

**What gap does it fill?** BAC-IN was formed from a need identified by black and minority ethnic users in recovery or seeking recovery to have their own forum that would acknowledge and work with their cultural, traditional, religious and spiritual values.

**Development:** It was established in 2003 by four ex-users as a self-help support group. In 2004 the project started working in Nottinghamshire to support black and minority ethnic communities and prisoners serving sentences and on release. The continuing support of professional champions from the DAAT partnerships and the substance misuse treatment system has been key to the development and sustainability of BAC-IN.

**Main activities:** BAC-IN aims to support the cultural needs of black and minority ethnic drug and alcohol users. They aim to empower members and help them to seek culturally appropriate help and advice to address their drug and alcohol problems. BAC-IN provides one-to-one support, group work, aftercare support for prisoners, a self-help support group, mentoring, peer advocacy and individual counselling, and is developing work to support prisoners in local prisons.

trusted by users. Such peer champions are able to access individuals and talk to them in places that professional workers may not be able to access. Professional champions within BUBIC have helped to develop peer champions by developing their self-confidence and self-esteem, and providing ongoing support, supervision and training.

### **PROJECT PROFILE: BUBIC (Bringing Unity Back in the Community)**

**Area:** Haringey, London

**Peer-led element:** entirely peer-led

**When:** all stages of the treatment journey

**What gap does it fill?** It provides peer-led support sessions in priority neighbourhoods to increase service user involvement in the delivery and planning of services.

**Development:** The work is funded through the DAAT partnership and New Deal for Communities. BUBIC promotes community-based peer-led support services. These are intended to enable the personal transformation of drug users by providing community-based activities that will aid their rehabilitation.

**Main activities:** BUBIC sessions are set up and run by ex-users. They run five groups a week at four different locations, including a mixed group and a women's group. BUBIC delivers sessions as part of the Drug Interventions Programme and has links to local prisons. They had over 1344 contacts with users and

- 3) Importance and development of peer champions:** Some peer-led approaches can become a hub or focus point for black and minority ethnic groups in the community because of the trust they develop with their specific users. Peer champions have a key role to play as they are often well known and

ex-users in the second half of 2005. BUBIC has won a number of community awards for its work, including the Community Safety Peace Week Award 2005 for the best crime reduction initiative. The Metropolitan Police Service identified the work of BUBIC as crucial in developing a cross-partnership strategy focused on the aims of the drugs strategy, including reducing crime.

- 4) **Developing family-based approaches:** Issues around stigma can leave drug users from black and minority ethnic communities feeling isolated from friends and families. Contributors have highlighted the importance of peer-led approaches and projects working with black and minority ethnic communities liaising with families to reduce stigma and anxiety. For example, they highlighted that South Asian drug users may be younger, with a shorter history of drug use, and that they are more likely to be living with their families. Therefore, DAAT partnerships should not only consider the users' needs, but also, where appropriate, provide support for families and carers.

## CASE EXAMPLE

**Name:** Samara  
**Gender:** female  
**Age:** 23  
**Ethnicity:** mixed heritage

**Project:** BAC-IN

**Key quote:** *'BAC-IN accepted me as I was and the people there believed in me. I have now learned to accept myself and I have some self-belief.'*

**Background:** Samara is a single parent with long-standing alcohol and drug problems. She suffered underlying issues surrounding self-identity, low self-esteem, depression and anxiety, and has a history of self-harm and broken relationships.

**Type of support accessed:** counselling and peer-led support

**Individual outcomes:** Samara has been abstinent from alcohol and drugs for over 18 months. She found that the support she received gave her increased confidence, self-esteem and a more positive outlook on life, and her relationships have also improved. She has gone back to college and is doing volunteer work with disadvantaged groups.

## CASE EXAMPLE

**Name:** Mo

**Gender:** male

**Age:** 30

**Ethnicity:** British Pakistani

**Project:** BAC-IN

**Key quote:** *'It was hard work in the past having to explain about my cultural background, but I felt I belonged at BAC-IN which took away these barriers. There's more to life than drugs. Make the most of life and God will take care of the rest.'*

**Background:** Mo has a long history of drug and alcohol problems, with episodes of imprisonment for violence, theft and car offences. He had a poor experience of schooling and is long-term unemployed.

**Type of support accessed:** counselling and peer-led support

**Individual outcomes:** Mo found peer-led support gave him enhanced self-esteem, self-acceptance and self-compassion. It increased his confidence and spiritual knowledge and beliefs. He is currently doing volunteer work and studying human development and complementary approaches to healing. He has been abstinent from alcohol and drugs for over two and a half years.

## 1.4 Faith communities

The number of faith-based organisations delivering support to drug and alcohol users has increased in recent years. Faith-based organisations can play a vital role in raising awareness and challenging

discrimination in a community. DAAT partnerships should consider developing alliances with faith communities to raise awareness and increase the understanding around drug issues within these communities. Such alliances can also help to develop support structures for drug users within faith communities.

### Common barriers:

- 1) **Limited awareness of faith communities:** Professionals within the DAAT partnership or the substance misuse treatment system may have limited knowledge and understanding of the value of faith-based support that can be provided through faith communities. DAAT partnerships need to recognise that some people prefer faith-based support as it can offer access to a wider community, which helps to reduce stigma and isolation, and increase access to support and mentoring opportunities.

### Developing peer-led approaches with faith communities:

- 2) **Importance and development of a professional champion:** Professional champions can play a key role in supporting the development of faith-based peer-led approaches by educating the faith community about drugs and drug use. This will assist the faith community to understand how to work with and support drug users. For example, in Lancashire an imam from one of the local mosques has undertaken drug awareness training provided by the local DAAT partnership. He is now helping to improve and raise awareness in the community.

The example below highlights another approach which offers peer support from a faith perspective and has helped individuals access and build their own support network.

### PROJECT PROFILE: Zacchaeus Project

**Area:** North Nottinghamshire

**Peer-led element:** coordinated by a police officer with a Christian faith

**When:** all stages of the treatment journey

**What gap does it fill?** The coordinator identified in 2000 that many users, carers and service providers in North Nottinghamshire were not aware of Christian treatment resources. Some users and carers reported being dissuaded by service providers from accessing these resources because of the religious focus of the provision.

**Development:** The project now runs two local voluntary drop-ins. It has inspired six similar projects (four in Nottingham, one in the West Midlands, and one in Scotland). The project receives funding from the county DAAT. The project's voluntary workers include professionals from the police, drug services and other health services.

**Main activities:** The project provides care and support, including hot meals, works in partnership with local service providers and statutory bodies, and regularly receives referrals. It refers people to Christian drug services, maintains contact with those in rehabilitation, provides safe homes for weekend breaks from rehabilitation, facilitates family contact, provides assistance with accommodation, education and employment, and helps people to access local churches for support and friendship.

- 3) **Importance and development of peer champions:** Peer champions also have a key role to play. They are often well known and trusted by users, and are also trusted within their faith communities. For example, peer champions were instrumental in establishing and developing NAFAS, an aftercare support network in London.

### PROJECT PROFILE: NAFAS (NAFAS translates as *Breath of life and freedom*)

**Area:** Tower Hamlets, London

**Peer-led element:** Aftercare support groups are entirely peer-led.

**When:** Aftercare support is available to individuals completing NAFAS treatment programmes and to drug-free clients from other treatment services.

**What gap does it fill?** The aftercare support project is part of a larger service. NAFAS is a multifaceted specialist resource established to meet the needs of the Bangladeshi Muslim community in Tower Hamlets. NAFAS aims to be in tune with the cultural and religious orientation of its users. The vast majority of service users are young heroin smokers, 18% are women, and many live with their parents.

**Development:** Two users had been involved with other aftercare groups, but they found that they did not meet their cultural or religious needs, so they established an aftercare support network in 2003. When the Drug Coordinators for the New Deal for Communities Regeneration heard about the group they recognised that it filled a gap in service provision in the area. The group has received mainstream DAAT funding since 2005.

**Main activities:** The level of support offered depends on client need, but can include talk therapies, acupuncture and support groups. It offers routes into accredited training and access to volunteering to build confidence and abilities and help orientate ex-drug users towards involvement in community activities, community work, voluntary work, employment or further education.

## CASE EXAMPLE:

**Name:** Paul

**Gender:** male

**Age:** 31

**Ethnicity:** white European

**Project:** Zacchaeus Project

**Key quote:** *'I owe my life to the Zacchaeus team.'*

**Background:** Paul started using drugs in his early teens when his parents' marriage broke up. He subsequently drifted into crime, became a prolific offender in burglary, car crime and shop theft, and served several short sentences. He was disowned by his family and was living in a burnt-out flat.

**Type of support accessed:** Paul started attending the Zacchaeus Project drop-in in November 2003. He enjoyed the support given and was supported by one of the team members. He was attracted to the idea of Christian rehabilitation. He went to Teen Challenge, a rehabilitation centre in Wales. During this time the drop-in team maintained contact through phone calls, letters, emails and visits. A safe house was provided for local home visits. On completing rehabilitation Paul was helped to find a flat owned by local Christians, and his support from peers has continued. He also has extended family support from one of the local churches.

**Individual outcomes:** Paul now works as a volunteer at Zacchaeus. He also works with the local prolific offender unit as a peer support worker. He gives presentations to local schools and youth groups and is training to be a drug worker. He also hopes to set up a local peer-led support group with another ex-user. Paul has been identified by the Probation Service as someone they would like to employ in the future as a peer mentor and it is likely that he will soon be working with them in a full-time paid post.

## 1.5 Families of drug users

### Common barriers:

- 1) **Isolation and stigma:** Many families and carers experience feelings of shame for having a child or family member who is a drug user. As a result of such feelings some find it difficult to seek help and support, and this can result in isolation for many. Those that do seek support may find that there is no specific information source locally for families and carers. Families' and carers' groups also have to be cautious about how they promote themselves, the support offered and the venue. Some peer-led groups have faced objections from local people about holding meetings, which has left people attending the group feeling unsafe.
- 2) **Lack of recognition and support for specific family members such as grandparents or young people:** Grandparents or young people may need specific advocacy and support, but are often ignored. These family members can feel pressurised to

assume caring roles. For example, grandparents may take on the role of 'carer' to prevent their grandchildren being taken into care. However, this role is reluctantly assumed for some, because of poor health, work commitments, or the impact on other relationships. Financial difficulties may also be incurred, including the cost of transport resulting in limited access to group-based forms of support.

### Developing peer-led approaches for families of drug users:

- 3) **Importance and development of professional and peer champions:** Some DAAT partnerships have appointed dedicated user and carer advocacy posts, which act as professional champions to develop support for families and carers.

Peer-led groups for families and carers are also developed, thanks to the determination of a few parents with drug-using children who start supporting one another. This was the case in the establishment of both PINS and PANIC, which are outlined below.

#### PROJECT PROFILE: Parents in Need of Support (PINS)

**Area:** Hartlepool

**What gap does it fill?** PINS provides support, advice and information to parents and carers of people involved in drug use. It also works alongside statutory bodies in providing support to users.

**Development:** PINS was established in 1996 by two parents after months of searching for an agency that provided support to parents and carers. PINS employs a full-time project manager, a support and advice worker, and nine volunteers.

**Main activities:** PINS offers practical and emotional support, befriending, mentoring, drop-in facilities, drug awareness and aftercare support training courses, parenting skills courses and advice. PINS has also developed a working partnership with two young people's counselling and mentoring services to enhance 'fast-track referrals'.

### **PROJECT PROFILE: PANIC (Parents and Addicts Against Narcotics in the Community)**

**Area:** Stockton-on-Tees

**Peer-led element:** entirely peer-led

**When:** stages of the treatment journey

**What gap does it fill?** PANIC was established in 2000 by two mothers of drug users, as there were few local services available at the time.

**Development:** It is funded by Stockton DAAT, and the majority of staff are carers or ex-drug users who live in the local community.

**Main activities:** PANIC offers two separate services, one for carers and one for users. Support is delivered in separate locations, but the types of support offered to both groups are the same. These include counselling, key working, advocacy, advice, buddy support, alternative therapies and educational courses. No appointments are necessary, there are no waiting times and home visits are available where requested.

5) **Establishing flexible support and approaches:** A range of flexible approaches needs to be considered to support the diverse needs of family members affected by another family member's substance misuse problems.

- **Grandparents:** The needs of grandparents may require flexible and specific forms of support because of isolation or travel difficulties. Support such as one-to-one sessions, outreach and satellite support group meetings, and telephone support should be considered.
- **Black and minority ethnic families:** Families and carers from black and minority ethnic groups are concerned about receiving support and advice that reflects their diverse cultural and religious needs. For example, contributors have stated that some Muslim women have requested support as they are considering living separately from their drug-using partner and are concerned about the cultural and social implications of this action.

## CASE EXAMPLE

**Name:** Vera

**Gender:** female

**Age:** 68

**Ethnicity:** white British

**Project:** PINS

**Key quote:** *'Peer support has provided emotional support and practical information which has helped me feel a greater sense of control.'*

**Background:** Vera's grandson, Simon, aged 19, had been using heroin for four years. Because of constant conflict and stealing from home, his parents and siblings could no longer cope, and this led to his grandmother caring for him. When Vera first contacted PINS she was under constant pressure and finding it difficult to cope, which was resulting in further conflict. Obtaining support was difficult because she lived in a village on the outskirts of Hartlepool and because ill-health prevented her from travelling to local support groups.

**Type of support accessed:** Vera received home visits on a weekly basis and was provided with emotional support, advice and information. PINS also referred a young person's drug worker to her grandson Simon.

**Individual outcomes:** Vera is now better able to cope, thanks to the weekly support, and her grandson is receiving alternative therapy while awaiting treatment.

## 1.6 Rural communities

### Common barriers:

- 1) **Limited awareness of diverse needs in rural areas:** Evidence suggests that assumptions are often made that the problems that exist in urban communities do not occur in rural communities<sup>7</sup>. Issues such as poverty and drug use are often unseen and unacknowledged. As a result persuading DAAT partnerships and commissioners to recognise and accept the need to fund peer-led approaches in rural communities is often difficult.
- 2) **Dispersed populations:** Populations in rural areas are more dispersed and transport links are often poor. This can result in additional costs of delivering peer-led approaches in rural areas.
- 3) **Stigma and isolation:** Contributors believe that negative reactions to drugs and drug users are more evident within some rural communities. This means that it may be more difficult for ex-drug users to move on from past behaviour or labels. This could result in isolation for some ex-drug users who choose not to engage with their local community for fear of being identified as a drug user. In addition, individuals who are lesbian, gay or bisexual or from black and minority ethnic communities may experience twofold isolation.

<sup>7</sup> Pugh, R. (2005) *Working in Partnership in Rural Areas* in Carnwell, R. and Buchanan, J. (eds) *Effective Practice in Health and Social Care: A partnership approach*, Maidenhead: Open University.

## Developing peer-led support and approaches in rural areas:

- 4) **Establishing flexible support and approaches:** A range of flexible approaches should be considered if the needs of drug users in rural communities are to be met.
- **One-to-one support:** DAAT partnerships should consider providing one-to-one support for those who are unable to travel to meetings.
  - **Providing transport:** DAAT partnerships should consider providing funds to meet transport costs. For example, county council services such as Dial-a-Link, in which council transport can be booked for a nominal fee, can be used to take some people to meetings.
  - **Telephone support:** Support needs can be intermittent and hard to predict, as they often arise at times of crisis not only in the life of the individual but also in the lives of others. A number of projects have developed telephone support that can operate at different times and in different ways. For example, an approach called 'telephone trees' has been used by a number of peer-led groups. This approach involves the establishment of a group of peers who regularly call each other to offer support. Contributors to this practice guide have identified this as a valuable means of support in rural areas for dispersed populations.

- 5) **Selecting appropriate venues and ensuring safety:** Contributors highlighted the importance of safety, accessibility and discretion in finding appropriate venues for peer-led approaches in rural areas. For example, meeting dates and times can be advertised in local papers but arrangements about the venue should be made individually over the telephone to ensure that only group members or new invitees know the details. The importance and impact of flexible approaches and of finding appropriate and safe venues is illustrated by the work of OASIS.

### PROJECT PROFILE: OASIS

**Area:** Lincolnshire

**Peer-led element:** entirely peer-led

**What gap does it fill?** aimed at parents and carers and provides support across Lincolnshire

**Development:** OASIS was established in 2000. The project champions are two parents who both had a drug-using child in the family. They placed a small advertisement in the local newspaper announcing that they were going to have a support group meeting. On the first evening twelve families turned up. A professional champion from the local drug clinic offered a space to meet and gave his time voluntarily. Without this support the project would not have had a venue.

**Main activities:** OASIS provides one-to-one support, satellite support groups, a 24-hour telephone helpline, advocacy, prison support and education. OASIS also supports grandparents who are carers. This group often requires greater levels of outreach as many grandparent carers are struggling financially and some have health issues that make travelling difficult.

**Individual outcomes:** The support provided has been both practical and emotional. She has been able to meet with other grandparents in the same position and to gain support from these alliances. Feeling more in control has been good for Julie's health and well-being and she has been able to continue caring for her granddaughter and maintain contact with her sons.

## CASE EXAMPLE

**Name:** Julie

**Gender:** female

**Age:** 45

**Ethnicity:** white British

**Project:** OASIS

**Background:** Julie lives in a small seaside town, which is isolated and has very poor public transport links. Julie cannot afford taxis and is unable to drive. She has two sons who are both using heroin. She is also the primary carer for her granddaughter.

**Type of support accessed:** one-to-one peer support, grandparents support group, advocacy with the courts, supported visits to prison to see sons

## 1.7 Prisoners and ex-prisoners

This section is based on the contributions from three different peer-led support schemes, and also on a good-practice guide for prisoner peer support produced by the former HM Prison Service Safer Custody Group<sup>8</sup>, now part of the National Offender Management Service (NOMS) Health and Offender Partnerships.

It is important to note and recognise that requirements and restrictions when operating peer-led support and approaches in prison may differ by institution. Nonetheless contributors highlighted the need to learn more about how existing and new peer-led approaches can be effectively promoted within prison among prisoners and prison staff to build on the lessons learnt so far.

### Common barriers:

- 1) **Security issues in prisons:** The development of peer-led approaches in prisons can raise concerns around security for prison staff. It may also create suspicion among prison staff and other prisoners. For example, prisoner peer advisors (prisoners providing advice and guidance to

<sup>8</sup> *Prisoner Peer Support: good practice guide for peer support schemes*, London: HM Prison Service.

other prisoners after having receive training and support to do so) have some freedom of movement, but could be put under pressure by other prisoners to move items around the prison.

- 2) **Access to prisons by ex-prisoners from peer-led projects in the community:** Some community-based peer-led projects use people with a criminal record to deliver peer-led approaches. However, some of these individuals have faced difficulties in gaining entry to some prisons to provide peer-led support.

### Developing peer-led approaches for prisoners:

- 3) **Importance and development of professional and peer champions:** The HM Prison Service guide suggests that a small working group should be appointed to plan the principles of introducing a peer-led scheme within a prison. This working group should include at least two prisoners, prison staff, a manager, a Samaritan, and staff from other disciplines as appropriate. It also advises that some members of the working group should visit prisons that have an established scheme to look at lessons learnt. ASIAN is an example of a peer-led project that has been supported and developed by professional and peer champions from the Drug Interventions Programme (DIP), a prison officer and Reading User Forum.

### PROJECT PROFILE: ASIAN (Asian Service in Alcohol and Narcotics)

**Area:** Reading

**Peer-led element:** ASIAN is peer-led, with the support of prison staff. The governor supported the project from the outset and a prison officer was allocated to work with the project.

**When:** in prison and on release

**What gap does it fill?** Pakistani prisoners and drug users had difficulties in re-integrating into their community in Reading because of the stigma of drug use. Accordingly, the founding members of ASIAN who are ex-users, ex-offenders or prisoners from the Pakistani community formed a peer support group.

**Development:** The group is supported by UCLAN, Reading User Forum and Reading DIP.

**Main activities:** The group supports Pakistani prisoners both in prison and on release. The prisoners who provide peer support have received training and support and developed new skills through conducting a needs assessment. The prison staff now have a better understanding of the needs of Pakistani prisoners, which has reduced tensions and helped this group to articulate their needs. The number of Pakistani prisoners entering treatment in this prison (HMP Bullingdon) has increased.

- 4) **Support and training to peer champions in prisons:** It is vital that prisoners taking on the role of peer champions receive appropriate support and training if they are to effectively deliver peer-led provision in prisons. St Giles Trust actively recruits prisoners and provides support and training to enable them to deliver advice and guidance to other prisoners. The Trust also provides them with ongoing support and supervision.

#### **PROJECT PROFILE: St Giles Trust – Prisoner Peer Advice Services**

**Area:** South East

**Peer-led element:** professional-led organisation with prisoner peer advisors

**When:** in prison and on release

**What gap does it fill?** It trains prisoners to deliver advice to other prisoners.

**Development:** St Giles Trust appointed three staff to set up a housing advisory service in HMP Wandsworth in 2000. With a throughput of 4500 prisoners per year the team could only provide advice to a small number of those who needed it. For that reason, in 2002 the Trust began to train prisoners to deliver information, advice and guidance on accommodation issues to other prisoners.

**Main activities:** St Giles trains prisoners to NVQ Level 3 in advice and guidance. Prisoners gain real job experience while completing the qualification and typically complete it in six to nine months. St Giles also links foreign national prisoners and peer advisors. This helps it to recruit peer supporters from a wide area and allows the project to support prisoners more effectively. In 2004 it won the Andy Ludlow Award for good practice in homelessness services. The project expanded from 2 to 15 prisons, including male and female prisons, and prisons with differing security statuses and profiles. St Giles supports released prisoners into permanent and stable employment.

- 5) **Addressing security issues in prisons:** The Prison Service guide outlines a number of requirements that must be complied with in the selection of prisoners to peer-led support schemes to ensure safety and security of staff and other prisoners. These include agreed security clearance and risk assessment, suitability criteria, selection and training procedures, induction periods and the requirement for a signed contract. Requirements may vary in different prisons. Offenders who have committed offences against children are not eligible to join some peer-led projects in prison, e.g. those run by the Samaritans. The Prison Service also has a written commitment to recruiting peer supporters from black and minority ethnic groups.

## CASE EXAMPLE

**Name:** Boomer

**Gender:** male

**Age:** 26

**Ethnicity:** British Pakistani

**Project:** ASIAN

**Key quote:** *'Peer support is about building relationships, communication and the opportunity to interact with all sorts of different people. It offers the understanding and empathy that only fully comes from experience.'*

**Background:** Boomer used to supply Class A drugs and was jailed for three years for conspiracy with intent to supply. He was a gang leader and had been to jail on several occasions for a number of different offences. He has also received a number of Anti-Social Behaviour Orders.

**Type of support accessed:** He became involved with a community engagement research project in prison and received training and support to conduct a needs assessment. This allowed him to develop new skills and confidence.

**Individual outcomes:** Now out of prison, Boomer has joined ASIAN and is seeking work in the health and social care sector. He has also completed numerous drug-related courses and has obtained an NVQ Level certificate in drugs and drug effects.

## 1.8 Lesbian, gay, bisexual and transgender (LGBT) populations

### Common barriers:

- 1) **Isolation:** LGBT populations may face discrimination on the basis of their sexuality and some people are concerned about being identified as lesbian, gay or bisexual. This could result in isolation or even depression for some ex-drug users who feel that they have no-one to talk to about their sexuality and no identified community or group from whom to seek support.
- 2) **Hostility, physical attacks and verbal abuse:** Some contributors reported incidents of vandalism to buildings and cases of physical and verbal abuse. This raises issues around how to ensure the safety of those attending groups or attempting to access support.

### Developing peer-led approaches for LGBT populations:

- 3) **Establishing flexible support and approaches:** A range of innovative and flexible approaches needs to be considered if the diverse needs of LGBT drug users are to be met.
  - **Email and telephone support:** Email and telephones can ensure that people who prefer not to attend groups are still able to access support. These approaches have been successfully used by Hart Gables.

## PROJECT PROFILE: Hart Gables

**Area:** Hartlepool

**Peer-led element:** entirely peer-led

**What gap does it fill?** The group provides a support group for lesbian, gay, bisexual and transgender populations in and around Hartlepool.

**Development:** It was established in 1997 after an individual identified that there was little in the way of support or provision for the local LGBT community.

**Main activities:** The types of support offered include social support and leisure activities, email and telephone support operating five days a week, advice services, advocacy and representation. Between January and December 2004 more than 400 people accessed the project and there were more than 1400 contacts. The project also works closely with other support groups and community organisations to represent the LGBT community in local forums.

- **Information technology, e.g. discussion boards:** Durham University LGBT Association has its own board for discussion among members. This allows people to talk to students from other institutions on shared boards by following links to a separate board. People can read messages as a guest, but to post messages they have to register. This simply involves providing a real email address to confirm the registration. This is an automatic

process and people do not have to disclose any personal information if they prefer not to. There is also a women-only board that is password-protected.

## PROJECT PROFILE: Durham University LGBT Association

**Area:** Durham

**Peer-led element:** entirely peer-led

**What gap does it fill?** The LGBT Association is a group within Durham Students Union run by lesbian, gay, bisexual and transgender students.

**Development:** It was established in 1994, and a democratically elected executive committee runs it on a day-to-day basis. The group operates a common-sense confidentiality code that they ask everyone to follow.

**Main activities:** The main activities are in three areas.

- **Social:** There is a large number of social events in safe venues.
- **Welfare:** Services offered include a regular drop-in where peer-led support is available in complete confidence, free safer-sex supplies and literature, and information on a wide range of subjects.
- **Representation:** The association represents LGBT interests within the student union, the National Union of Students and other relevant organisations including the police. An annual awareness week is organised.

## CASE EXAMPLE

**Name:** James

**Gender:** male

**Age:** 21

**Ethnicity:** white British

**Project:** Hart Gables

**Key quote:** *'The group is good because you can talk to people without being frightened about being judged. People understand what you are going through.'*

**Background:** James is a young man living on his own. He is estranged from his parents because of his sexuality. His neighbour wrote obscene letters to him and pushed excrement, used needles and other rubbish through his letterbox because he 'hated gay people'. He had attempted suicide because of the loneliness and isolation he experienced. After his last attempt the Cleveland Police LGBT Liaison Officer referred him to the group for support.

**Type of support accessed:** James's first contact with the group was the Monday-night drop-in, where he was able to meet and talk to people in a safe and fun environment. He asked to be referred to the counselling service run by the group. The group was also able to advocate on his behalf with a housing association to have him re-housed.

**Individual outcomes:** James has been able to make friends with whom he can socialise and receive support. He currently has a partner and is involved in a range of voluntary activities.

## 1.9 People with mental health problems

As many as one in six adults in Britain suffer from some form of mental illness<sup>9</sup>, making the condition as common as asthma. There are a number of identified community benefits offered by peer support, including reducing the need for services, increasing community engagement, reducing stereotypes and stigma, and creating positive changes in mental health services.

### Common barriers:

- 1) **Stigma and isolation:** People with mental health problems can suffer stigma, prejudice and hostility, which can lead to their isolation within their local communities. Black and minority ethnic groups are disproportionately represented within mental health services. However, lower numbers of black and minority ethnic people access mental health support groups. In fact black and minority ethnic people with mental health issues have reported misunderstanding, discrimination and racism in some support groups. Contributors also suggest that there may be particular stigma around mental health in some black and minority ethnic groups.
- 2) **Support from DAAT partnerships and commissioners:** Commissioners in some parts of the country commission traditional professional mental health services to provide all support and provision to people with mental health problems, e.g. through mental health trusts. Contributors suggest that reluctance to commission more flexible approaches may be due to perceived potential risks. In

<sup>9</sup> [www.nhs.uk/England/AboutTheNhs/Nsf/MentalHealth.cmsx](http://www.nhs.uk/England/AboutTheNhs/Nsf/MentalHealth.cmsx)

some DAAT areas this limits the development of appropriate peer-led approaches for this group of people.

### Developing peer-led approaches for people with mental health problems:

- 3) **Flexible approaches and supporting choice:** There is no doubt that there are difficulties around developing peer-led support for this group of people, but Hackney Joint Development Initiative (HJDI) have demonstrated that it is possible to set up a range of simple and effective methods of support with very little funding.

HJDI made small grants available for groups of people to develop peer support initiatives around mental health. There were insufficient funds to pay for wages but enough funds to pay for the rental of rooms and promotional materials. The initiative was promoted widely within community centres and other mental health groups. As a result a number of different forms of support were established, some based around ethnicity and some around diagnosis. For example, a group of people who were having panic attacks wanted to develop a system of support so that someone would check in with each person daily, so they established and provided such a system of support via telephone contact.

The development of peer support groups for specific populations that emerge out of locally identified needs should also be considered, as in the case of RAMA.

### PROJECT PROFILE: RAMA (Asian Men's Mental Health Support Group)

**Area:** Wolverhampton

**Peer-led element:** entirely peer-led

**What gap does it fill?** The Asian Men's Mental Health Support Group is a user-led self-help support group that provides culturally sensitive support to Asian men who are experiencing problems around mental health.

**Main activities:** Current and ex-service users meet every two weeks and can take part in a range of activities, including discussing their respective mental health issues and experiences, developing social networks, promoting self-esteem and confidence, advocacy and advice, leisure activities, arts and creativity, and access to, and use of, a personal computer. The group operates on principles that recognise individuality and encourage people to reflect on, and develop their own solutions to, their respective issues. The group offers a safe environment that provides physical and mental well-being and helps the men to achieve their goals, realise their potential and reduce their social isolation in an environment where they can enjoy themselves. The group also campaigns for changes to mental health services that make a real difference and that reflect the needs of the South Asian male service users. These include:

- developing a greater awareness and knowledge of mental health and its consequences within the local South Asian community;

- ensuring that mainstream mental health services are more responsive to the needs of South Asian mental health service users and carers;
- empowering South Asian service users and carers to influence planning and service delivery around mental health.

### CASE EXAMPLE

**Name:** Art

**Gender:** male

**Age:** 34

**Ethnicity:** South Asian British

**Project:** RAMA (Asian Men's Mental Health Support Group)

**Key quote:** *'RAMA has led me to find my voice as a mental health service user.'*

**Background:** Art has used mental health services since 1997. The first few years after his mental health diagnosis were difficult, mostly because of isolation and poor community support.

**Type of support accessed:** Art initially doubted the viability of an Asian men's group. However he found the group rewarding and learned more about other Asian men's experience of mental health services.

**Individual outcomes:** His levels of personal identity, self-worth and confidence have all grown. Attending the Asian men's group also gave him the confidence to attend another support group and to attend mental health training courses.

## 1.10 HIV-positive populations

The following information is based on two projects that provide support to people who are HIV-positive. Although neither of the groups is drug-specific, many of the barriers and support needs identified are not unique to HIV-positive populations. The development of peer-led support for those with HIV has been championed by many HIV-positive individuals, their partners and families. This support has developed to meet needs that may not have been provided through professional routes, including providing shared understanding and experience of diagnosis, managing treatment regimes and providing emotional support.

### Common barriers:

- 1) **Limited understanding of available support:** Some individuals who are heterosexual and diagnosed as HIV-positive may be reticent about going to peer-led support groups around HIV because they are unaware of what services or support networks are actually available. They might also be concerned that they will be the only heterosexual person in attendance.
- 2) **Stigma and confidentiality:** Stigma around HIV-positive status can have major implications for individuals and their families within their local communities and in the workplace. People can also be concerned about confidentiality issues when attending support groups that are part of the NHS treatment system.

## Developing peer-led approaches for HIV-positive populations:

- 3) **Access to up-to-date information on HIV treatment:** Usually only specialist clinics have the most up-to-date information and it can be difficult for other NHS service providers and patients to keep abreast of new information<sup>10</sup>. The HIV organisation i-base operates as a national information resource and has helped people by providing and sharing relevant information.

### PROJECT PROFILE: i-base

**Area:** London (information distributed nationally)

**Peer-led element:** entirely peer-led

**When:** all stages of HIV treatment

**What gap does it fill?** It provides information and advocacy on HIV issues, including treatment, to HIV-positive populations and NHS service providers. It aims to help people understand what is happening to their bodies and how they may need to adjust their lifestyles to accommodate these changes.

**Development:** It was established in 2000 by a group of HIV-positive individuals. These individuals educated themselves on how HIV treatment works in order to be actively involved in making decisions

about their own treatment needs and to help other people to do this. It began by faxing information to hospitals and doctors about drugs in a publication called 'Dr-Fax'.

**Main activities:** i-base produces a number of publications about treatment and pragmatic treatment passports, drug adherence charts and guides to managing drug regimes. Some of these publications are translated into various languages including English, Chinese, French, Greek, Italian, Portuguese, Russian, Serbian, and Spanish. A telephone information service also provides information about HIV treatment.

- 4) **Providing responsive and accessible support in places where people attend for treatment:** Flexible and accessible support could be provided through the Expert Patients Programme (EPP). The EPP is an NHS-based training programme that provides opportunities to people who live with long-term chronic conditions to develop new skills to manage their condition on a day-to-day basis. The EPP was established in 2002 and is based on research from the US and UK, which shows that people living with chronic illnesses are often in the best position to know what they need in managing their own condition. Provided with the necessary 'self-management' skills they can make a tangible impact on their disease and quality of life more generally. More details on the EPP can be found in Annex B.

<sup>10</sup> Trautmann (1994) *The European Peer Support Project: Peer Support As A Method For AIDS Prevention in IDU Communities*, [www.drugtext.org/library/articles/traut4.html](http://www.drugtext.org/library/articles/traut4.html)

- 5) **Information technology (IT):**  
IT can be used to develop virtual communities that allow people to engage in forums in confidence and at convenient times. This can be particularly important in rural areas, where those who are HIV-positive may be more dispersed and find it difficult to access services.
- 6) **Targeting support to specific groups:**  
Groups such as the Organisation of HIV-Positive African Men (OPAM) aim to support people from a specific community in a culturally appropriate manner to help reduce stigma and the isolation experienced by HIV-positive African men.

### **PROJECT PROFILE: OPAM (Organisation of HIV-Positive African Men)**

**Area:** London

**Peer-led element:** entirely peer-led

**When:** all stages of HIV treatment

**What gap does it fill?** There is a strong sense of stigma around HIV in the African community and OPAM provides support to HIV-positive African men appropriate to their cultural needs.

**Development:** The project was established in 2000 by some African men who believed that their cultural needs were not being addressed within generic HIV services. Most of the funding is from the local Primary Care Trust.

**Main activities:** OPAM provides up-to-date information on treatment, medication and dietary issues. Members of the group offer informal support, social activities, and support to people around family issues and in getting back into education and employment. The members also represent the views and needs of African men who are HIV-positive in relevant forums.

# 1. Key Principles for DAAT Partnerships and Commissioners

The aim of this practice guide has been to provide DAAT partnerships and commissioners with examples of transferable practice that will assist them in commissioning, developing and delivering peer-led approaches to meet the diverse needs of those who have left treatment.

The funding available through the DIP main grant specifically requires the development of relapse prevention support, including peer support for drug users leaving treatment. However, there is a risk that peer-led projects may be viewed as low-cost service providers and funded at the expense of other aftercare service in the statutory and voluntary sectors. Peer-led services must be provided as part of a continuum of treatment and care and funded to complement the work of professional services. Some minimum requirements are set out below.

### DAAT partnerships should aim to:

- map the availability of and need for aftercare provision, including peer-led approaches, to ensure that diverse needs are met;
- promote to the local community the benefits of aftercare support both for the client group and for the community as a whole;
- work with local community groups to maximise support and service provision for ex-drug users;
- ensure cross-representation on the DAAT and local user groups to ensure that diverse needs are taken into account;
- raise awareness of aftercare needs and provision through joint planning, joint working, and training sessions between

drug treatment services, CJITs, housing providers and providers of education, training and employment.

### DAAT partnerships and Regional Government Offices should aim to:

- ensure that cross-boundary DAAT arrangements are in place on access to aftercare provision, including peer-led support where appropriate;
- discuss with local and regional partners the potential for regional support networks for peer champions.

### DAAT partnerships should aim to ensure that CJITs and treatment providers:

- include an assessment of aftercare needs as part of their care planning review process, and provide drug users with information on and access to provision, including peer-led approaches;
- support those leaving prison by ensuring that CARATS services referring to CJITs provide information to inform continuity of care, and where appropriate provide information on community peer-led approaches as part of release planning.

The following checklist of questions can be used as a guide to help develop supportive commissioning practices and practical support to initiate or further develop effective peer-led approaches to meet the needs of their local communities.

### Assessment of local aftercare needs

Ongoing consultation and effective engagement with ex-users, users in treatment and local communities can provide the knowledge and understanding

that enables an informed evaluation of local needs. However, the process needs to be systematic and ongoing, and not just a one-off exercise, and should include representation from a wide range of diverse groups, such as families and carers; ex-offenders; lesbian, gay, bisexual and transgender groups; and those who have a disability. Individuals will look for support from non-drug-focused peer-led projects. Accordingly, DAAT partnerships may wish to consider the following questions:

- What mechanisms are in place for consulting with drug misusers, carers and families, local communities, peer-led projects and approaches and treatment services to assess local needs?
- How often do such consultations take place?
- Is there any local system for collecting, analysing and monitoring data around diversity that will assist in identifying needs and gaps in current service provision?
- Has any specific targeted consultation process been carried out with any members of local diverse communities in order to engage these groups and to assess any unmet needs?
- What information is currently available on aftercare provision in the local area, including peer-led approaches?
- What peer-led approaches are being used and accessed, when, and by whom, in the local community?
- Have needs been identified that are not met by current peer-led projects and approaches?

- Is any information on peer-led programmes available in prisons within the region?
- Are the monitoring and consultation mechanisms a regular aspect of local treatment planning to gather information and address unmet needs?

### Planning issues

Identifying a clear pathway from treatment into aftercare provision as early as possible is vital to meeting local diverse aftercare needs. Peer-led support is a key element in supporting people on this pathway, and DAAT partnerships need to consider the following questions:

- What practical support and resources are currently provided to peer-led approaches and projects?
- What specific resources (financial or human) are required to develop current and new approaches and projects?
- Can newly identified needs be met by making existing peer-led support projects more accessible or adapting what is currently provided?
- What support do existing peer-led projects receive from treatment services and other services providers (such as mental health and social services)?
- Who are the local peer champions and what support do they need?
- Is appropriate support provided for the promotion and development of support systems and networks for local peer champions?
- Should some peer-led approaches and projects be run by paid peer champions or by unpaid volunteers?

- Have any professional stakeholders been appointed to work alongside the peers and their projects to support development?
- Should a specific post be developed with responsibility to help initiate and support user-led projects?
- What potential risks need to be considered and planned for?
- Have monitoring requirements been agreed, and are they proportionate and sensitive (e.g. they do not turn people away from using the peer-led project or approach)?

### Providing practical support and funding

Peer champions have used very different funding strategies to set up projects. These include:

- fund-raising (e.g. organising dances and events);
- one-off grants from interested businesses, individuals or charitable organisations;
- small grants from the local substance misuse treatment system (e.g. social services or the drug and alcohol team);
- non-financial support from the local substance misuse treatment system (e.g. venues for meetings and office space).

However, many of these strategies are often not sufficient to ensure sustainable income for their ongoing development. If sustainable peer-led approaches are to be available locally, peer champions may need support and practical help from

professional stakeholders, so DAAT partnerships may wish to consider the following questions:

- Is assistance needed around finding a venue or location for the project, especially when a project is first set up?
- Is funding (e.g. a small grant) needed for the setting up of a project?
- Is help needed with accessing information on funding sources, bidding for grants or completing application forms for ongoing funding?
- Is funding or practical help needed to access leisure or social activities?
- Is assistance required around promoting the project or approach to specific groups, e.g. to people in prison, as well as in the community?
- Is practical help needed in the development of policies and procedures, the writing of funding bids, the development of monitoring systems, etc?
- Is funding required for facilitators, administrators or other posts for local peer-led projects and approaches?
- Do peer-led projects need help in brokering proportionate contract monitoring and performance management arrangements that are transparent, accessible and realistic?
- Is assistance required in accessing supervision, training and development opportunities, such as attending local, regional and national conferences and networking with other peer-led support projects and approaches?

Finally, DAAT partnerships and commissioners should remember that successfully commissioning peer-led support may require a different approach to the commissioning of drug treatment services. They should endeavour to have:

- a commitment to innovation;
- flexibility;
- a certain level of risk management;
- an acceptance that sometimes peer-led approaches will require intensive support and direction; and
- a willingness to develop partnership with other DAATs and key stakeholders across regions to ensure the development of appropriate peer-led provision for diverse communities.

# ANNEX A

## Glossary of Terms

### Drugs

The term 'drugs' refers to psychoactive drugs including illicit drugs and non-prescribed pharmaceutical preparations.

(Source: *Models of care for treatment of adult drug misusers*, NTA 2002)

### Misuse

The term 'misuse' refers to the illegal or illicit drug taking or alcohol consumption which leads a person to experience social, psychological, physical or legal problems related to intoxication or regular excessive consumption and/or dependence. Drug misuse is therefore drug taking which causes harm to the individual, their significant others or the wider community. By definition those requiring drug treatment are drug misusers.

(Source: *Models of care for treatment of adult drug misusers*, NTA 2002)

### Substance misuse

Substance misuse is drug and/or alcohol taking which causes harm to the individual, their significant others or the wider community. By definition those requiring drug or alcohol treatment are substance misusers.

(Source: *Models of care for treatment of adult drug misusers*, NTA 2002)

### Treatment

This term describes a range of interventions which are intended to remedy an identified drug-related problem or condition relating to a person's physical, psychological or social (including legal) well-being. Structured drug treatment follows assessment and is delivered according to a care plan, with clear goals, which is regularly reviewed

with the client. It may comprise a number of concurrent or sequential treatment interventions.

(Source: *Models of care for treatment of adult drug misusers*, NTA 2002)

### Substance misuse treatment system

The term 'substance misuse treatment system' is used to refer to all treatment organisations involved in the commissioning and delivery of treatment for substance misusers, including organisations from the statutory, voluntary and independent sectors.

### Aftercare

Aftercare is the package of holistic support that needs to be in place after a drug misuser leaves custody, completes a community sentence or leaves treatment. It involves access to additional support, including housing, managing finances, rebuilding family relationships, learning new skills, access to employment and access to social support networks.

(Source: *Key Messages*, DIP 2006)

Aftercare can also be described as:

- drug-related support, such as relapse prevention, support groups and individual support for those wishing to remain drug-free, and access to user groups and advocacy mechanisms (such as Narcotics Anonymous); or
- non-drug-related support, such as access to education or training, support from advisory services, helping develop social networks and employment support.

Such aftercare follows the completion of care-planned drug treatment.

(Source: *Models of care for treatment of adult drug misusers: Update 2006*, NTA 2006)

## Diversity

Diversity means 'difference' – difference across race, gender, disability, sexual orientation, faith and age. It is the recognition that not all people are the same and that people have different, equally valuable skills, experience and knowledge to offer.

(Source: Home Office website – Equality and Diversity ([www.homeoffice.gov.uk](http://www.homeoffice.gov.uk)), 2006)

## Diverse needs

The term 'diverse needs' is used in this practice guide as a recognition that not all drug users are the same and that people have different, but equally important, needs within local communities that should be addressed.

## Ex-user

The term 'ex-user' is used in this practice guide as a shorthand to refer to people who have completed treatment, whether in prison, in a residential setting or in the community.

## User involvement

The term 'user involvement' refers to the building of an equal partnership with drug treatment service users. It recognises that those in treatment and those who have identified a need for treatment have the right to become involved in activities that affect their health and well-being. It respects the unique expertise and experiences of users

and understands the health, esteem and other personal benefits which involvement can bring.

(Source: National Treatment Agency website – User Involvement ([www.nta.nhs.uk](http://www.nta.nhs.uk)), 2006)

## Peer-led approaches

The terms 'peer-led approaches', 'peer-led support', and 'user-led' or 'peer-led projects' are used interchangeably. They refer in this practice guide to aftercare support projects that are led by people who have themselves completed drug treatment programmes.

## Family

The term 'family' includes any person who is significant in the life of the drug user, irrespective of the biological, social or legal status of the relationship.

## Carer

The term 'carer' is used in this practice guide to refer to anyone who cares for or offers support on a regular and personal basis to another individual (whether or not they have formal carer responsibilities or status).

## Family and carer involvement

The term 'family and carer involvement' refers to the building of effective partnerships with the carers and family members of drug users. This involvement recognises the different needs and issues of importance to carers and families.

(Source: National Treatment Agency website – Carer Involvement ([www.nta.nhs.uk](http://www.nta.nhs.uk)), 2006)

## Commissioning

Commissioning is the strategic activity of assessing needs, resources and current services, and developing a strategy to make the best use of available resources to meet identified needs.

(Source: *Commissioning Standards Drug & Alcohol Treatment & Care*, Health Advisory Service 1999)

## Joint commissioning

This is the process in which two or more organisations act together to coordinate the commissioning of service(s), taking joint responsibility for the translation of strategy into action.

(Source: *Commissioning Standards Drug & Alcohol Treatment & Care*, Health Advisory Service 1999)

## Black and minority ethnic

Various terms are used to refer to the many diverse communities in England. Summarising diverse communities and ethnic backgrounds using an all-inclusive definition cannot fully describe the complex and subtle factors that contribute to an individual's identity or ethnic background. However, the term 'black and minority ethnic' is used in this practice guide to acknowledge the diversity that exists within these communities, and includes a wider range of people who may not consider their identity to be 'black', but who nevertheless constitute a distinct ethnic group. It is also the term currently most commonly used and recognised by DAAT partnerships and the substance misuse treatment system.

### What is the EPP?

The Expert Patients Programme (EPP) is an NHS-based training programme that provides opportunities to people who live with a long-term chronic condition to develop new skills to manage their condition better on a day-to-day basis. Set up in April 2002, it is based on research from the US and UK over the last two decades which shows that people living with chronic illnesses are often in the best position to know what they need in managing their own condition. Provided with the necessary 'self-management' skills, they can make a tangible impact on their disease and quality of life more generally.

The EPP is one among a range of new policies and initiatives to modernise the NHS and to emphasise the importance of the patient in the design and delivery of services. Fundamental changes are taking place to empower patients, recognising that patients and professionals each have their own areas of knowledge and expertise and need to work together.

This vision for a new patient-centred NHS reflects the fact that the predominant pattern of disease in this country during the second half of the twentieth century and the beginning of the new century is of chronic rather than acute disease. Diseases such as cancer, heart disease, stroke and arthritis can and do kill, but more often they are a burden that people carry from the middle years of their lives into old age.

### What is an expert patient?

Expert patients are people living with a long-term health condition who are able to take more control over their health by understanding and managing their condition, leading to an improved quality of life.

### Benefits of becoming an expert patient

Expert patients:

- feel confident and in control of their lives;
- aim to manage their condition and its treatment in partnership with healthcare professionals;
- communicate effectively with professionals and are willing to share responsibility for treatment;
- are realistic about the impact of their disease on themselves and their family;
- use their skills and knowledge to lead full lives.

Further information on the EPP can be found at [www.expertpatient.nhs.uk/](http://www.expertpatient.nhs.uk/)

## ANNEX C

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