National Treatment Agency
for Substance Misuse

Making a difference to drug treatment services
Notable examples of user and carer involvement

Part of the ‘Extending empowerment’ information kit - 3rd November 2004
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As part of the work done for the Audit Commission's report *Drug misuse 2004 – reducing the local impact*, a number of examples were identified where the involvement of service users and carers is helping to make a real difference to the quality of drug treatment services. This document identifies some of these examples.

**The Alliance - influencing at a national level**

The Alliance aims to support people who receive prescribed drugs for the treatment of their drug dependency. The organisation actively promotes the participation and involvement of prescribed drug users in their work and the Alliance aims to give drug users a real voice in the drug policy debate.

These aims are achieved by a number of methods and approaches, including:

- Providing peer advocacy programmes in treatment services.
- Training users and professionals in the principles of advocacy and user involvement.
- Collecting feedback from service users about their experiences of treatment and prescribing services to help inform discussions with providers and policy makers.
- Lobbying service providers and government to involve drug users in the development of treatment services. The Alliance has representatives on several official working parties, including the National Treatment Agency's Expert Group on Prescribing. The organisation also advises two large clinical research projects on methadone prescribing.
- Promoting more accurate images of people who use prescribed drugs - to the media, to the government and the general public. In November 2001, the Alliance gave evidence to the Home Affairs Select Committee at one of its hearings into the effectiveness of the Government's drug strategy.
- Producing high quality information and advice for medical practitioners and allied professionals about substitute prescribing.
- And hosting conferences.

For further information visit: [http://www.m-alliance.org.uk](http://www.m-alliance.org.uk)

**Opening Doors Experts by Experience Group – service effectiveness and collaboration**

The Opening Doors Experts by Experience Group was set up in 2003, by the NTA in collaboration with NIMHE, to enable people with personal experience of substance misuse services to become increasingly involved in informing and shaping the development of their own services. Its original membership was drawn from users and carers who became involved in local Opening Doors projects and who were relatively new to the ‘involvement movement’. The group aims to build the capacity for service users and carers to participate in the development of services nationally, regionally and locally. It also aims to forge collaboration between service users and carers across the mental health system, thereby modelling the need for closer co-operation between services.

The group has made important progress both nationally and locally. For example by building relationships with Drug Action Teams they have increased the involvement of users in local decision making.

In addition to the informal learning provided by networking, the group has also provided a forum for training, which has increased members’ skills and confidence to work with and influence professional leaders.
Calderdale Users Forum – service delivery

Service users have important views about the effectiveness of services and, in Calderdale, the service users forum has been able to change the way in which services are traditionally delivered. An example of their efforts is the work the group has done in relation to the local needle exchange.

As a result of concerns about the service, the Calderdale Users Forum was commissioned to conduct research with peers about the needle exchange. Over 150 users were interviewed to get their views and recommendations, such as changing the opening hours, were then made to the local Drug Action Team. The changes to the needle exchange were implemented in 2003 and since then real improvements have been noted.

These improvements include an increase in the number of people using the service (from 180 to 500 users), reduced waiting times and more users going onto enrol on treatment programmes.

For further information e-mail: cuf.cuf@lycos.com

Sheffield Family and Friends Alliance – involving carers

The Sheffield Family & Friends Alliance brings together a group of representatives from Sheffield family support groups and agencies. The alliance meets regularly to share information and look at ways in which they can work together to meet the needs of families.

The Family & Friends development worker co-ordinates the group meetings and sends out minutes to members. The worker also represents the Advisory group at regional & national National Treatment Agency meetings, feeding in the views of families to influence regional & national policy.

There is constant communication with the Sheffield Drug Action Team, who places the views of families and service users high on their agenda and takes them into consideration when developing action plans.

Key achievements of the group include: producing a family support video called “Putting it into Words”, developing specific support for grandparents, providing volunteering and training opportunities and holding conferences so families can find out how their views have helped make a difference.

As well as working at a local level, the Alliance has also taken part in national initiatives such as being consulted on ADFAM’s work to develop a set of Quality Standards / Codes of Practice for family support groups.

For further information call: 0114 2736881

Oxfordshire User Team (OUT) – training and advice

OUT is an independent user led charity that provides peer led activities including educational workshops, support groups and advocacy in Oxfordshire.

As well as producing advice materials and representing users on key DAAT working groups in Oxfordshire, OUT has been commissioned by the NTA to help boost user involvement in the South East.

The charity is helping to find and train user representatives, is providing advice to established user groups and is helping to ensure that users are involved in decisions about local treatment plans.
The two year scheme has already conducted work in five DAAT/DAT areas and eventually aims to have covered every area in the South East.

For further information e-mail: admin@oxfordshireuserteam.org.uk

Stockton Reality Check Group - commissioning

Stockton DAT has made positive moves to increase user and carer involvement. As well as having representation on the DAT’s commissioning panel and main committee, a carer also chairs the DAT Reality Check Group.

The representation of users and carers has had a positive impact on local commissioning. In Stockton the views of carers and users has helped lead to an increased investment in inpatient detox, residential rehabilitation and halfway housing.

For further information call: 01642 898999.

Other notable examples of carer and user involvement

Traffasi – research

Traffasi, an independent drug users consultancy, have worked with several DAAT’s to look at the needs of ‘hard to reach’ drug users. Traffasi have conducted needs assessments in both rural and urban settings, focusing particularly on non service using, marginalized groups. They have successfully built involvement groups for women, BMEs and crack users.

For further information visit: www.traffasi.com

Cumbria DAT – staff recruitment

Cumbria, along with several other DATs, has introduced the policy of involving users in recruitment. By ensuring that users sit on staff interview panels both DATs and users have reported the view that better appointments are now being made.

For further information e-mail: info@cumbriadat.org.uk

Wirral DAAT - publicity and information

The input of service users is invaluable when it comes to designing effective information materials around prevention, access and treatment. In Wirral, users are routinely consulted over style, wording and design whenever new information is produced by the local DAAT.

For further information call: 0151 651 0011 Ext 382

PADA - education and training

Parents Against Drug Abuse (PADA) was set up 15 years ago on the Wirral, Merseyside as a service for the parents and families of people who misuse drugs. It now offers a range of services from education in schools to prison visits. The organisation runs a national helpline for parents and often makes referrals to local DAATs.

For further information visit: www.pada.org.uk

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