



***National Treatment Agency
for Substance Misuse***

Being heard

Notable examples of user and carer organisations

Part of the 'Extending empowerment' information kit - 3 November 2004

Being heard

Notable examples of user and carer organisations

As part of the work done for the Audit Commission's report *Drug misuse 2004 – reducing the local impact*, a number of user and carer organisations were identified. In highlighting examples of notable practice in England, user and carer groups can learn valuable lessons from each other and become both more involved and more effective in the planning and delivery of improvements to treatment and services.

Users

Calderdale Users Forum (CUF)

CUF is a voluntary organisation founded by current and ex-service users to ensure that their views are taken into account by treatment providers and planners. As well as helping to inform the work of the local drug action team (DAT), CUF is commissioned by the DAT to undertake peer education and advocacy within substance misuse services. CUF also undertakes commissions for other organisations, for example, CUF was involved with the University of Huddersfield in a drug mapping exercise.

As well as advocating on behalf of users, being involved in staff development and advising the local DAT on issues such as service delivery and treatment planning, CUF has also been involved in:

- **Mentoring** - in partnership with Lifeline, CUF works with the Outlook Mentoring Scheme which trains people who have been involved in substance misuse as mentors. To date, eight people have completed the programme. Some of these have mentored staff in probation services and the job centre. This has resulted in a positive shift in staff attitudes and knowledge of drugs.
- **Communication** - CUF members act as peer communicators to the drug-using community. They explain information to users in terms they can understand, for example, explaining the dangers of overdosing and blood-borne diseases. They are in touch with non service users and often help get them into treatment.

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

ARCH Initiative and Wirral DAAT user involvement

As a result of the user involvement programme run by the drug initiative ARCH and the local drug and alcohol action team (DAAT), users now sit on many of the important DAAT groups and have been successful in influencing:

- **The treatment plan for 2003-04** - they were able to persuade the DAAT to change their policy and allow people to access detox and rehab outside the area and to provide a budget to pay for it. As a result of this users now have more choice.

- **Training** - users suggested that they should be trained in first aid to reduce the numbers of drug-related deaths. Four sessions of ten people each have taken place.
- **Publications** - users are now routinely consulted before leaflets from DAATs and some service providers are produced.
- **Residential services** - user feedback from residential services suggested that users wanted more activities. This has led to the DAAT putting in place plans to employ an activities officer.
- **Hospital facilities** - users said that having a soft drinks machine in a hospital encouraged them to consume drinks with caffeine so this was replaced with a water machine.
- **The ARCH Aftercare service** - the day care programme was changed as a result of user feedback.

For further information e-mail: mail@arch.u-net.com

Oxfordshire User Team (OUT)

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

Successes include:

- Publication of resources including *Practical guide to user involvement and peer education*, a manual used throughout the south east region to help users become effective in their work with DAATs.
- User representation on key DAAT working groups.
- An advocacy service.
- Ongoing series of peer-led workshops on harm reduction.
- Personal development of OUT volunteers.
- Advising other user groups in the South East.

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

Experts by Experience

The *Opening Doors* Experts by Experience group was set up in 2003, by the NTA and NIMHE (National Institute for Mental Health in England), 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 involved in local *Opening Doors* projects and who were relatively new to the 'involvement movement'.

The group aims to:

- build capacity for service users and carers to participate in the development of services nationally, regionally and locally.
- forge collaboration between service users and carers across the mental health system, thereby modelling the need for closer co-operation between services.

The group provides a forum for people with similar hopes and experiences to support and learn from one another. This has helped build confidence, reduce isolation and maintain people's energy and enthusiasm to lead and promote involvement regionally and locally.

The effectiveness of local user and carer involvement has been strengthened because the Experts by Experience group has enabled different models of user and carer involvement to emerge, thereby building a national body of knowledge and expertise on 'what works'.

For further information visit: www.nta.nhs.uk

Methadone Alliance

The Alliance supports people who receive prescribed drugs for the treatment of their drug dependency.

They actively promote the participation and involvement of prescribed drug users in their work. Service users and professionals work together as equals in a unique initiative to give drug users a real voice in the drug policy debate by:

- providing peer advocacy programmes in treatment services
- training users and professionals in principles of advocacy, user involvement, and overdose awareness
- collecting feedback from service users about their experiences of treatment, and their perceptions of the quality of current prescribing services and using this feedback to inform discussions about treatment policies with providers and policymakers.

For further information visit: www.m-alliance.org.uk

FAB (Feelings, Attitudes, Beliefs)

FAB is a consultancy of ex drug users who work through 'Talkin Communities' in the Nottinghamshire Drug Action Team area. It is a voluntary network and is dedicated to representing the views of drug users, ex drug users, carers and the wider community. The organisation is funded by both their local DAT and the NTA.

The services FAB provides include support to other emerging user groups and training for users so they know how to get their points across.

For further information e-mail: talkincommunities@vodafone.net

Other organisations noted by the Audit Commission for their user involvement include:

- Cumbria Drug Action Team
- Halton Drug Action Team
- Glentop (stimulant services) and Manchester Addiction Services Empowered (MASE) user group.
- Staffordshire Voice

Carers

Sheffield Family & Friends Alliance

The Sheffield Family & Friends Alliance brings together representatives from Sheffield family support groups and agencies. They meet regularly to share information and look at ways to work together to meet the recognised needs of families.

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

There is constant communication with the Sheffield Drug Action Team, which places the views of families and service users high on its agenda and considers these when developing action plans.

Successes by the Alliance include:

- Involving and consulting with families to help develop ADFAM's set of quality standards / codes of practice for family support groups.
- Producing a family support video and training package called "Putting it into Words".
- Developing support for grandparents to meet their specific needs.
- Providing a variety of training and volunteering opportunities for families.
- Hosting a yearly conference to report back to families on how their views have made a difference.
- Developing a user and carer framework document, explaining how the DAT involves users and carers in the decision making.

For further inform call: 0114 273 6881

PANIC

PANIC (Parents and Addicts Against Narcotics in the Community) is an independent user group funded by Stockton DAT.

Activities include:

- complementary therapies
- support groups for families
- a user group.

A member of PANIC also chairs a sub group of the local DAT called The Reality Check Group which comments on all aspects of the DAT's work from the perspective of the user. The group has been highly effective in changing practice and promoting improvements in services. It is recognised nationally as good practice in user involvement.

For further information contact: 01642 898999.

Carers Against Substance Abuse

Carers Against Substance Abuse (CASA) was formed in 2003 to provide advice and support to the families and partners of users in Gateshead. Ten members of the organisation have already received accredited drugs awareness training, which has helped to provide an understanding of substance misuse issues. CASA has also been consulted over the local treatment plan and has had two members elected to the North East Regional Forum.

Plans are in place to involve CASA in a needs assessment of services, as well as electing a member to the DAT's joint commissioning team.

For further information call: 0191 202 2252

Clouds' Families Plus

Part of the charitable organisation Clouds, the work of Families Plus is devoted to family members and others who want help in understanding and coming to terms with the effects of living with the substance misuse of others.

Initiatives include:

- brief residential family programmes
- therapy tailored to meet the needs of individuals, couples or families
- family support groups

- aftercare
- workshops and training for professionals.

For further information visit: www.clouds.org.uk/family.htm

Hetty's

Hetty's is a support network for parents, carers, family and friends of illicit drug users.

Services include:

- confidential telephone support
- individually prepared information packs as and when required
- one-to-one support - in callers home or a place of safety
- group self-help meetings.

For further information visit: www.hettys.co.uk

Lifeline

Lifeline is a non profit-making organisation and a registered charity that helps people who use drugs and the families of people who use drugs.

Lifeline has a range of activities including:

- partnership work
- harm reduction
- service delivery
- development work including joint work with drug users
- research
- innovative pilots
- community involvement
- social inclusion and education
- volunteer work.

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

Oasis

Oasis is a project based in Lincolnshire to support families who have a family member using drugs or alcohol.

Services include:

- confidential telephone support
- group, self-help meetings
- weekly, open access
- bereavement support.

For further information visit: www.drugsupport.co.uk

PADA (Parents Against Drug Abuse)

Parents Against Drug Abuse began as a community-based parent and family support group in Ellesmere Port in Cheshire in 1994. Since then, the work of the organisation has expanded with services now including a 24-hour helpline, as well as training and support to families and carers.

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

Adfam

Adfam is a national organisation which works with the families of drug users.

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

The African Families Foundation (TAFF)

TAFF works with African community organisations, and with voluntary and statutory agencies, to facilitate best use of ideas and resources.

For further information visit: www.africanfamilies.net

Families Anonymous

This is a worldwide fellowship of relatives and friends of people involved in the abuse of mind-altering substances, or with related behavioural problems. A number of local groups operate across the UK.

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

Famfed (Families Federation)

A national organisation which supports family support groups of drug users.

For further information e-mail: natfedfam@aol.com

National Treatment Agency
5th floor, Hannibal House,
Elephant and Castle, London SE1 6TE.
Email: nta.enquiries@nta-nhs.org.uk
Website: www.nta.nhs.uk