

nsun



network

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ABOUT NSUN

NSUN is the National Survivor User Network. We network service user groups and organisations in England. NSUN was launched in February 2007, with grant funding for five years from Comic Relief and the Tudor Trust.

As the news pages that follow show, we have been very busy since our first Network newsletter last summer. Our management committee has completed the formal processes to establish NSUN as an independent registered charity, and we are now fully autonomous. We are really grateful to Together: Working for Wellbeing who hosted us in the early days while we found our feet.

Our membership is growing – a 50% increase in the last 12 months. We are in the process of redesigning our website to improve its capacity to support communication between and about our member groups and regional networks. We also have four new management committee members (see page 2).

Following on the success of our North East and South East network hubs, we are in the process of commissioning similar regional NSUN networks in the North West and West Midlands, and are applying for funding for a London regional network co-ordinator post.

Another major development is our success in winning the contract to take forward service user and carer involvement in the National Mental Health Development Unit (the Department of Health agency that has replaced NIMHE). We put in a joint bid with five other organisations and Phil Partridge started work with us as project co-ordinator, based in the NSUN London office, in December 2009. Phil is working part-time on the eight-month project.

All in all, a very productive six months, and a busy 2010 ahead.

Sarah Yiannoullou, NSUN manager



Sarah Yiannoullou (right) with Patrick Vernon, chief executive of the Afiya Trust, one of NSUN's partners in the NMHDU bid

WHO ARE WE?

There are nine of us on NSUN's management committee.



Tina Coldham (chair)

Tina has been involved in NSUN from the planning stage. She became a user activist through setting up self-help groups and being part of a local campaigning user group. Since 2003, she has worked for the Health and Social Care Advisory Service (HASCAS) on various national projects. Tina is an experienced trainer, lecturer, researcher and consultant, and currently co-chairs the Partner Council of the Social Care Institute for Excellence.

Carolyn Anderson

Carolyn has been a mental health service user for many years. She is on the committee of a peer support group in Sevenoaks, Kent. She runs a Buddy Scheme in Maidstone that pairs buddies as mentors with psychiatric nurses, junior doctors and the police. She is on the Rethink South East Region management committee and that of the Service User Involvement Peer Support and Development Group. She also runs a bipolar disorder group on www.linkedin.com with over 90 members worldwide.



Anne Beales MBE

Anne Beales is currently director of service user involvement at Together: Working for Wellbeing (Together). Previously she set up and co-ordinated the Capital Project Trust, a service user led training and support group in West Sussex, for which she received an MBE in 2007. She is service user consultant to the NHS Confederation Mental Health Network. She also sits on the National Committee for Gender Equality and Women's Mental Health.

Alisdair Cameron

Alisdair Cameron is team leader at Launchpad, the mental health service user involvement project for Newcastle upon Tyne, co-chair of the Northumberland, Tyne and Wear Service User & Carer Network, a director of NAGAS (Newcastle and Gateshead Arts Studio), vice-chair of MHNE (Mental Health North East), and a board member of UKAN (United Kingdom Advocacy Network).

Sue Haworth

Sue Haworth is a service user from the north west of England. She is active in local and regional service

user networks and has a particular interest in community mental health services, dual diagnosis and crime and mental health. She currently chairs Greater Manchester West Mental Health NHS Foundation Trust's user action team and is also a trust governor.



Kath Lovell

Kath Lovell is the National Project Development Manager with Emergence (formerly Borderline UK and Personality Plus). She has been involved in a number of service user involvement and training initiatives that draw on her personal experience of living with a diagnosis of personality disorder and of accessing mental health services, including Expert by Experience with the Henderson Hospital and service user researcher with St George's University.



Mike Llywelyn Cox

Mike is a mental health service survivor living in Norfolk, a user for over 40 years, and a retired Approved Social Worker. He was closely involved in early user led advocacy and worked with East Suffolk Advocacy Network (ESAN). Following retirement in 1999, he now works as a volunteer with several organisations, including mental health and older people's advocacy and The Norfolk Coalition of Disabled People.



Ian Muhammad

Ian's career has included work in youth, community, prison and the probation services. Most recently he was quality assurance manager in the service user involvement directorate of national mental health charity Together.

Clare Ockwell

Clare Ockwell was a founder member of SARA (the Society for the Advancement of Research into Anorexia), and helped run it for ten years before it merged with the Eating Disorders Association. She was a trustee of the EDA for five years, and in 1997 became a founder member of the CAPITAL project, a West Sussex service user training, research and peer support group, where she is now chief executive.

We have said a sad farewell to management committee member Angela Hill, who has had to step down from the committee. Her input will be missed.

We also have four members of staff based at our national office in London: Sarah Yiannoullou, NSUN manager; Amma Djan, administration and finance officer, Phil Partridge, our new part-time officer (see p1 news), and Soka Kapundu, our part-time operational accountant.



Patricia Chambers –
'Too often BME people get overlooked'

CHARTER FOR BME INVOLVEMENT

Catch-a-Fiya and NSUN's joint black and minority ethnic involvement project, Dancing to Our Own Tunes, is to publish a national charter to help other organisations improve their BME involvement processes. A steering group has been formed with 15 members who have met three times and have agreed a work plan and aims and objectives for the project.

The steering group decided to focus on producing a charter of quality standards to provide a best practice framework and model for NHS trusts and other organisations wanting to support and promote BME user involvement themselves. They are aiming to draft and finalise the charter by end of May 2010, when the funding for the project runs out. 'Unfortunately we just don't have the funds to do a national pilot across the country ourselves,' says Patricia Chambers, project manager at Catch-a-Fiya, who is leading the DtOOT programme. She hopes NHS trusts and third sector mental health organisations will want to take this work forward and roll the programme out across the country.

'Too often, the views and expertise of BME people get overlooked or excluded. This is about establishing a way for groups to work together so that non-BME organisations can benefit from BME user groups' expertise, and BME user groups can gain from the better resourced non-BME groups,' Patricia says.

NSUN GETS BUSINESS COACHING

NSUN staff and management committee are getting professional marketing and business development

advice from leading experts in the private sector, thanks to the disability organisation Disability Lib.

Disability Lib offers capacity-building grants and support to disability organisations. When NSUN applied for help Disability Lib referred us to Pilotlight, an organisation that arranges for teams of senior business people to coach small charities in organisational management and development.

NSUN has been matched with a team of three expert people from across the business sector who will be working with us for five months to create a new business strategy and marketing plan.

'We have identified finance and marketing as areas where we need most help,' says NSUN manager Sarah Yiannoullou. 'This will really help us think more clearly and strategically about our aims and objectives and how we present ourselves to the outside world.'

PEER SUPPORT FOR USER INVOLVEMENT

NSUN has launched a new national peer support and development group for service users/survivors working in service user involvement roles.

The group provides a forum for involvement workers to discuss practice issues and development and training needs and give each other peer support. It currently meets bi-monthly, and has a national membership and remit.

NSUN has commissioned service user consultant Dorothy Gould to facilitate the group. 'It can be a very isolated job, in the sense both that you are the only person doing it within an organisation and that other people don't always understand the role and why it is important,' she says. The response has been very enthusiastic: 13 people attended the first two meetings, from London, the North West, South East and West Midlands. They would welcome new members from the East Midlands, North East, South West, Yorkshire and Humber and East of England.

'The idea is to have one group member from each region who can feed back to other people within that region,' Dorothy says.

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PERSONALISATION

IN OUR OWN HANDS

'Personalisation' is the word used currently to describe the government's overall approach to the provision of all public services. Broadly, it is about individualised services, increased choice and greater individual say in public service provision. It is also about ensuring that everyone in any community has equal access to local public services and facilities such as transport, leisure, education and training, housing, health and employment opportunities, regardless of age or disability.

Personalisation in health and social care is about tailoring care and support services to a person's individual needs and offering greater choice about services, who provides them and how they are managed and paid for. It is about improving access to information, signposting and advocacy so that people know what is on offer and can make informed decisions about how best to meet their care and support needs.

The aspect of the personalisation likely to make the biggest change to people using mental health and social care services is the universal roll-out of personal budgets (see 'terminology' box). The government has said that it expects local authorities to have 30% of clients who are eligible for adult social services on a personal budget by March 2011. Nearly one third of local authorities intend to have all their clients on a personal budget by that date.

Studies of use of individual budgets and direct payments show that, broadly, 15% of users make radical changes to their support package when they get control of their funding, 50% make small changes, and the rest keep things as they are. The most common change is to move from mainstream day and residential care services to employing personal assistants and home helps. People also use their new freedoms to choose to spend their budget on a wider range of support and services – leisure, education, equipment and skills training, as well as direct care.

These changes will have a major impact on the way social care services are commissioned and managed locally. Service providers will have to offer a much more individualised service and a far more varied menu of options if they are to meet the demand for more individually tailored support. Small organisations, like the user-led groups who provide peer support and care services for people with mental health problems, are going to have to be able to market their services and negotiate individually



Showing the way

In Kent, voluntary sector organisation Signpost Kent is working with local authorities and PCTs, with funding from the Department of Health, to set up a brokerage framework to help people make choices about how they want to spend their personal budgets. They plan to use a co-production model, with local mental health service users helping to draw up a charter of good practice, quality standards and evaluation methods. Brokers could be freelance or employed by other organisations and will, Signpost hopes, come from a range of backgrounds and communities. Says Signpost director Jo Woollett: 'User groups and organisations may want to take on this role. We will expect brokers to demonstrate they can work within the charter of good practice before we register them, and service users will be able to access them from our register. We will also seek feedback from people at the end of the broker relationship about the service received.'

Canterbury and District Mental Health Forum is one of the local mental health user-led organisations working with Signpost Kent on the brokerage scheme. Says CDMHF director Mark Kilbey: 'Local authorities are struggling with how they are going to deliver the personalisation agenda. Service user groups are ideal to do this kind of work. We have the trust of service users, we know all the statutory and voluntary sector services and groups in the area.'

But, he says, there has to be some kind of national accreditation and quality standards assurance system in place if service users are not to be exploited. 'There is a lot of opportunity for people to be ripped off,' he warns.

<http://www.signpostuk.org>

with potential clients – a far more complex process than agreeing a single, block-buy contract with their local authority or commissioner.

Steve Nash is the author of a report published by the mental health voluntary sector umbrella group Mental Health North East that looked at the likely impact of personalisation and how voluntary sector organisations should be responding.¹ 'The personalisation agenda offers huge opportunities. Much more advice, signposting support, brokerage and user-led input are going to be needed and these are very positive opportunities for the user-led sector,' he says.

But user-led groups should be talking to their local authorities and PCTs now about their commissioning plans, and ensuring they are in a position to ride the personalisation wave. 'User-led groups really need to be making themselves familiar with the language and issues of personalisation. The way you provide your service needs to change. Groups need to do some detailed unit costing and produce strong outcome measures, using a model like Recovery Star, to demonstrate how your service has helped users towards recovery.'

'It's going to be a steep learning curve,' warns Alisdair Cameron, service user activist in the north east and a member of the NSUN management committee. 'User led groups frequently don't have the administrative capacity to manage single payments from individuals, as opposed to substantial grants. Many also lack the business and marketing skills. We can do it, but it won't be easy for us to flourish in this brave new world.'

Kevin Lewis, who leads on personalisation in mental health within the National Mental Health Development Unit (NMH DU), says that local authorities and health trusts will have to actively 'manage the market' to ensure that user-led organisations aren't wiped off the board. He sees a need for protocols to guide local authority and PCT commissioners who are under pressure to achieve commercial 'best buys.' 'Crude market testing could cause the demise of organisations that offer niche products,' he points out.

Robin Murray Neill, mental health and personalisation lead within the Department of Health Putting People First team, agrees. He says that local authorities may need to support user-led groups and organisations that don't have that administrative infrastructure. 'People find peer support easier to access and much more acceptable

than formal services. Local authorities and PCTs should be asking user-led groups what support they need in order to continue to function. They can't just say "Sorry, we have to take the lowest bid that gives us the bottom line of quality". They are going to have to see they have an investment in peer support groups flourishing.'

The government has issued guidance on user involvement under its Putting People First programme.² This requires local authorities to establish an 'enabling framework' of advocacy, peer support and brokerage systems 'with strong links to user led organisations' to support the personalisation agenda. If there are no ULOs locally, local authorities must establish a strategy to 'foster, stimulate and develop' them.³

Kevin Lewis believes strongly that these guidelines will ensure that mental health service users' views and the peer support services they uniquely provide will be accommodated within the new social and health care landscape. 'If we are serious about giving individual service users autonomy, and we have all-party parliamentary sign-up to that, it won't wash if we don't support service user groups,' he says.

¹ Nash S (2009). Personalisation: chaos or empowerment? Sunderland: Mental Health North East. www.mhne.co.uk

² Department of Health (2009). Putting people first: working together with user-led organisations. London: Department of Health. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_096859

³ Department of Health (2009). Transforming social care. LAC(DH)(2009)1. London: Department of Health. http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/LocalAuthorityCirculars/DH_095719

Terminology

Direct payments are a cash payment that individuals eligible for social care can request from their local authority to pay for their own care and support arrangements.

Individual budgets are like direct payments but can come from a wider range of funding sources and can be managed in different ways: by an individual as direct cash payment, or by a care manager, charitable trust or other third party on behalf of the individual.

Personal budgets are the term now being used to describe budgets that come from local authority social care funds. They include direct payments and allow the same flexibility as individual budgets as to how they are managed.

Personal health budgets extend the personal budget model to health services. They are currently being piloted in 24 mental health services, but are unlikely to be implemented widely until after 2012, when the pilot programme ends.

See *Putting people first: a shared vision and commitment to the transformation of adult social care* (HM Government, 2007). http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081118

GOOD PRACTICE

MORE USERS' VOICES, MORE USERS' CHOICES

These are just some of the pioneering service user groups that make up NSUN's growing membership.



Ian Wint (second from left) and Roots members, working together for change

Roots, South London

Roots is a new service user involvement project developed over the past 12 months within the Fanon mental health and well-being service of Southside Partnership, the south London based mental health and learning disabilities charity.

Roots emerged from the work of Fanon's community development worker Ian Wint and colleagues, who were concerned to boost the confidence and self-management skills of its clients. They employed two trainers to run a 12-week confidence building and leadership course for service users and, when the course finished, a small number said they wanted to form their own service user group and go on working together. Fanon provided them with further training in Mental Health First Aid and Recovery Star, and the plan now is for the group to lead activity programmes with service users on two adult psychiatric wards at Lambeth Hospital.

The initiative has been jointly funded by the hospital and Mosaic Clubhouse, which already runs activities on the wards. There are currently seven men and women in Roots. All are from black and minority ethnic communities, but it is not specifically a BME initiative. 'We believe people with lived experience of mental ill health and receiving services can work more effectively with people on the wards because they have been there and they know what it's like. The staff are very pleased because we are organising activities that give people confidence to get back into the community and this is relieving a lot of the stress on the wards,' says Ian.



Kuumba Foundation's user forum makes sure everyone's voice is heard

The Kuumba Foundation, West Bromwich

The Kuumba Foundation was founded in 1994 by a group of local voluntary and statutory workers concerned about

the lack of support in the community for African Caribbean people with serious mental health problems in Sandwell.

The Foundation started with a weekly drop in run by volunteers and now has nine full and part-time staff providing drop-in, outreach, employment support and counselling services to local African and Caribbean people. It also runs a young people's floating support service, in partnership with the Dorcas Housing Association.

It is funded partly by Sandwell PCT and partly by grant-giving organisations including the Lankelly Foundation and the Big Lottery.

Its user forum, Kujenga (African for 'to build') plays an active role in its service development and delivery. Service users are also encouraged and supported to volunteer at the Foundation, and many have moved on into other paid and volunteer work.

'Everyone has a role in Kujenga, either on a small or large scale. The group has given service users a sense of purpose on a social as well as a formal level and some have really benefited from feeling included in the decision making,' says Rosie Nembhardt, Kuumba Foundation well-being co-ordinator.

www.sacmhf.co.uk

LiVE in Brighton

LiVE stands for Listening to the Voice of Experience. Based within Mind in Brighton & Hove, it is funded by NHS Brighton & Hove. The role of the project is to support and promote user and carer involvement in improving local mental health services. It does this by creating and facilitating opportunities for service users to input their views and feedback at all levels of decision-making – from quarterly themed debates with commissioners to small focus groups on specific local issues.

LiVE provides training and ongoing peer and one-to-one support to ensure people are well equipped for their roles. It is also in the process of developing a 'best practice' training programme for service

providers, so that everyone can make the most of user involvement.

There are currently 49 service users and carers involved in LiVE. They work closely with the local Sussex Partnership NHS Trust and NHS Brighton & Hove, as well as with Brighton & Hove Council and local voluntary sector organisations. The project is supported by two part-time workers. Says project co-ordinator Julie Wright: 'We have a good relationship with local service providers. They respond positively to our requests for consultation and contact me regularly to organise focus groups and attendance at steering committees and other decision-making bodies. People seem to really appreciate the support we offer – the work can be challenging as well as rewarding and it's good to have a place to discuss it.'

www.mindcharity.co.uk



Pessimistic-Optimistic
by SUS member Aaron Rotherham

Speak Up Somerset

Speak Up Somerset was formed in 1998, with funding from a Mind Millennium Award, initially as a self-help campaigning organisation. More recently it has developed into a publishing group as well, and produces and sells a range of publications through its

www.artofrecovery.com

website. It has about 80 members, most of whom either have direct experience of mental distress or care for someone who has. It became a registered charity and company limited by guarantee in 2007.

Its aims are to encourage a positive approach to mental health by challenging stigma and promoting social inclusion, to provide information about mental health issues, and to promote the creativity and strengths of people affected by mental distress. It holds four members meetings a year and publishes a regular newsletter. It also produces its famed Positive Steps diary, illustrated with pictures by people with experience of mental distress and by carers. It has a turnover of about £10,000 a year, half from sales of publications and the rest from small grants.

Says SUS co-founder member Simon Heyes: 'We decided not to go down the road of having workers and an office, so we just have a PO box and the two websites. We are in the process of upgrading the artofrecovery.com website to make it more accessible and interactive. We did do some

involvement work with our local Foundation Trust but to be honest we found it a bit boring and it was hard to get people to go to meetings. We prefer to do our own thing around anti-stigma and awareness-raising activities.'

www.speakupsomerset.org
www.artofrecovery.com



CoolTan Arts believes
creativity helps mental health

CoolTan Arts

CoolTan Arts is a creative arts organisation for people with experience of mental distress. Based in Walworth, south London, it has six workers (full and part-time) and runs a huge range of arts workshops and activities. It was founded by a group of artists in 1990 in the disused CoolTan sun

lotion factory (thus the name) in Brixton, where their studios were based. It became a registered charity in 1997, and moved to its current premises in 2006.

CoolTan believes mental well-being is enhanced by the power of creativity. Workshops include painting and drawing, web design, photography and film, textiles, poetry and playwriting. In addition it offers community advocacy and runs a self-advocacy programme. It also takes part in events and exhibitions outside the centre and organises outings to galleries for its members. It is strongly user-led: half of its trustees have personal experience of mental distress, as do some of its workers. In an average month, about 500 people will come through its doors. Its funding comes from a wide range of sources, including Comic Relief and The Lottery Trust. It also provides volunteering opportunities.

CoolTan employs professional artists and arts teachers on a sessional basis to lead the workshops. 'The focus is on arts and creativity, not therapy. CoolTan is about allowing people to escape from institutional labels and helping them find an identity outside the mental health system,' says community involvement and advocacy co-ordinator Gin Atkins. 'We see creativity as a way for people to express themselves freely without being held back by conventions. Art of itself is therapeutic in a way that conventional art therapies don't allow.'

www.cooltanarts.org.uk
T 0207 701 2696

JOIN US!

NSUN's aims are to:

- facilitate active links between service user groups and individuals
- build capacity for service user groups
- broker and facilitate access to service users for purposes of influencing and informing policy-makers and planners
- develop a training programme in confidence building and committee, interview and staff training skills.

NSUN is here to help the individuals and groups that make up our very diverse user movement make their voices heard.

What do we offer?

Our protected Online User Database contains details of all our members, individuals and groups, so members can search for and contact others with similar interests.

We offer practical assistance for new groups with issues such as funding, budgets, managing staff, bidding for contracts and applying for grants.

We organise conferences, support user-led research and help our members to influence policy on behalf of service users at national and regional level.

We link groups and individuals seeking and providing training, to build capacity and support the independent voice of individual service users, groups and the movement as a whole.

For more information, visit our website at www.nsun.org.uk, or fill out and return the form below. Membership is completely FREE to individual survivor/users, groups and organisations. Ally members are asked to pay a fee on a sliding scale according to income.*

* Please contact NSUN for further details or visit www.nsun.org.uk

NSUN membership application form

I would like to join NSUN. I am a service user individual/group/organisation (please delete as appropriate). My details are as follows.

First name.....
Last name.....
Group/organisation name (for groups/organisations only).....
Address 1.....
Address 2.....
Town/City..... County..... Postcode..... Country.....
Phone number..... Fax..... E-mail address.....
Website.....

For groups

Region (tick all that apply)

National East of England East Midlands London Northeast Northwest South Central
South East Coast Southwest West Midlands

Type of organisation

Voluntary Statutory Independent sector Other
Other (please give details).....

Activities (tick all that apply)

Young people Forensics BME Depression Personality disorder Women Elderly Other
Other (please give details).....

Structure (tick all that apply)

Service user led (51% or more) Service user representation (50% or less)
Independent service user group (100% service user led)
Other (give details).....
.....

Mission statement/Description.....
.....

Number of members Number of paid staff

Please complete and return to: NSUN, 27-29 Vauxhall Grove, Vauxhall, London SW8 1SY T: 0845 602 0779 E: info@nsun.org.uk