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We are independent!

NSUN is the National Survivor User Network. We network service user groups and organisations in England.

A lot has happened since the last Network newsletter in the spring.

We became an independent charitable company in May. Together, which has 'hosted' NSUN since our launch, helped us enormously through the process of disengagement, ensuring it was smooth and well managed. We owe Together a huge thanks.

We will be holding our first annual general meeting in spring 2011 and will be inviting applications for new trustees to join the NSUN board.

Another big step forward is the launch of our new website in October. The website, at www.nsun.org.uk, now allows members to find groups around the country and keep up to date with policy developments, opportunities, events and campaigns.

We have also had a great response to our annual membership survey. Members say they feel a growing, stronger sense of identification with the Network. They find the regular information bulletins useful. However many think NSUN is too London-centred and would like more activity in all regions around the country.

Unsurprisingly members want NSUN have more influence and to lobby for better mental health services and resources and fight for the rights of users and survivors. We are hoping to recruit a communication and information worker to improve this aspect of our activities.

And last, but not least, we now have nearly 1000 members – a great start to our new independent status.

Sarah Yiannoullou, NSUN manager



NSUN staff (left to right) Showket Ali, Mulimba Namwenda, Soka Kapundu and Sarah Yiannoullou

Who we are!

There are seven of us on NSUN's board of trustees.

Tina Coldham (chair)

Tina has been involved in NSUN from the planning stage. She 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 runs a bipolar disorder group at www.linkedin.com and is on the committee of a peer support group in Sevenoaks, Kent, the Rethink board of trustees and the management committee of the Service User Involvement Peer Support and Development Group.

Alisdair Cameron

Alisdair is team leader at Launchpad, the mental health service user involvement project for Newcastle upon Tyne, and co-chair of the Northumberland, Tyne and Wear Service User & Carer Network.

Sue Haworth

Sue is active in local and regional service user networks and currently chairs Greater Manchester West Mental Health NHS Foundation Trust's user action team. She is also a trust governor.

Kath Lovell

Kath Lovell is the national project development manager with Emergence (formerly Borderline UK) and Personality Plus.

Dominic Makuvachuma-Walker

Dominic is currently working in the service user involvement directorate at Together – Working for Wellbeing. Previously he was the people participation lead, City & Hackney, for the East London Mental Health Foundation Trust.

Clare Ockwell

Clare is 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 would like to warmly welcome Dominic Makuvachuma-Walker, who has recently joined the board of trustees, and to say farewell and a big thank you to Ian Muhammed, Anne Beales and Mike Llywelyn Cox, who have stood down.

We want to extend special thanks to Anne for the support and commitment she has so generously given to NSUN for over four years. Anne was a founding member of NSUN and was a driving force behind the original proposal to establish a national service user network.

We also have five members of staff based at our national office in London: Sarah Yiannoullou, NSUN manager; Mulimba Namwenda, administration and finance officer; Phil Partridge and Fran Singer, NMH DU project co-ordinators, and Soka Kapundu, part-time operational accountant. Sam Allen also joined the team in July as an intern to support the development of the NSUN website and the National Involvement Project work.

Amma Djan, who worked with us as admin and finance officer from our launch, has sadly left us to work on a project abroad to widen her horizons – she is much missed.

Forensic settings fail on user involvement

Many NHS and independent sector forensic units are failing to provide adequate and meaningful opportunities for service user involvement. This is the damning conclusion of a review carried out by WISH on behalf of NSUN and published in October.

Just under half (74) of the 154 secure psychiatric hospitals identified in the survey returned the questionnaire. The responses showed low levels of user involvement and a widespread lack of robust structures that would give service users a meaningful say in how services are designed and delivered. In only 55% of NHS hospitals was there a member of staff with specific responsibility for service user involvement.

The most common type of forum for service user involvement was the weekly community meeting (96%), followed by the patient's council (47%). The issues dealt with were mainly day-to-day concerns, such as smoking, activities, food, and the ward environment. Many units lacked any mechanisms for feedback or to evaluate effectiveness of these forums.

The report makes several recommendations – not least that all forensic hospitals should have a designated service user involvement lead post, and a senior manager with specific responsibility for user involvement. NSUN says forensic units also need clear guidelines on good practice and mechanisms for ensuring feedback and assessing the effectiveness of user involvement structures and forums.

NSUN will use the survey findings to bid for funds for further research into embedding user involvement in forensic settings.

The full report is published on the NSUN website at www.nsun.org.uk.

Strategic partner programme

NSUN has been chosen, in coalition with seven other national mental health organisations, to join the Department of Health's third sector health and social care strategic partner programme. The programme was set up by the Department of Health to improve communication between policy makers and third sector organisations in the field. The appointment is for one year. The programme also includes



organisations from the other main health and social care user/client groups, not just mental health. 'This is a really useful forum as we meet regularly with other national organisations across the health, disability, learning disabilities and mental health sectors to advise and influence Department of Health decisions,' Sarah Yiannoullou, NSUN manager, said.

User involvement workers group looks ahead

NSUN's national peer support and development group for service users working in service user involvement roles has continued to meet bi-monthly and is looking for further funding to continue into 2011.

The group currently has a membership of about 20 people, from all except three England regions. 'What is emerging is an awareness of the importance to people in these roles to be able to meet and talk to each other. The other important element is development and we are currently looking at training that members could provide,' says Dorothy Gould, who facilitates the group.

The aim is to have members from all the England regions, and to develop local networks and organise local and national events. 'We are looking at mechanisms for that and funding implications,' Dorothy says.

Contact Dorothy Gould on **020 8340 3029** e dorothygould.org.uk@hotmail.co.uk

BME involvement charter launched

NSUN's black and minority ethnic involvement project, Dancing to Our Own Tunes, has published a national charter and guidelines to help other

organisations improve their BME involvement processes. The charter has been developed with the Catch-a-Fiya mental health service user/survivor network. It is intended to help NHS trusts and other mental health organisations build on the strengths of BME service users and actively involve them in their policy and decision-making structures. It also aims to combat stigma and discrimination and promote trust and partnership working between generic and black and minority ethnic user/survivor-led organisations.

The project's next stage is to promote awareness and use of the charter and guidelines to drive up BME user involvement and establish its standards for good practice. 'We will be encouraging our Catch-a-Fiya network to use the charter as a training tool to promote BME service user leadership and involvement. The charter also provides a set of standards so that individuals now have something to point to that states how things ought to be,' says Denise Forde, mental health programme manager at the Afiya Trust.

The Dancing to Our Own Tunes report and charter can be downloaded from www.nsun.org.uk

National involvement partnership

NSUN has been working with the National Mental Health Development Unit (a Department of Health agency that helps trusts implement government policy priorities) to improve service user involvement in its structures and decision-making.

NSUN is part of a consortium that also includes the Mental Health Foundation, the Afiya Trust, the Equalities National Council, Together, Attend and the Social Perspectives Network.

NMHDU will cease operating in March 2011 but the plan is that the involvement work will become a fully independent and sustainable National Involvement Partnership (NIP). NIP will maintain a database of local, regional and national contacts who will be able to respond to requests for consultation and involvement from the new consortia and organisations replacing PCTs and the existing NHS commissioning and delivery structure.

Fran Singer is now leading the project, as Phil Partridge has had to reduce his hours due to home caring commitments. Fran can be reached on fran.singer@nsun.org.uk tel **0845 602 0779** or **0207 820 8982**

FRIENDS IN DEED

Peer support isn't new – people with mental health problems have always been an important source of support for each other. However statutory mental health services have begun to realise the potential benefits for service users and to invest in peer support. User-led groups have also started offering formal peer support, as evidence grows that it is an effective way to help people recover and manage their mental health.

Recent years have seen a number of peer support initiatives emerging across the UK, fuelled by the increasing strength of the user-led sector, the growing influence of the recovery approach and the government's drive towards greater personalisation and self-directed support.

There are two main kinds of formal (also known as 'intentional') peer support: support provided by mental health service user groups set up specifically for that purpose (e. MDF: The Bipolar Organisation and the Hearing Voices Network), and support provided by people with lived experience of mental health problems who are employed in NHS trusts and voluntary sector mental health agencies to work with clients.

Reading Resource, for example, is a voluntary sector community mental health service in Berkshire, run by the mental health charity Together. In addition to offering work experience opportunities for service users in its cafe, it employs 11 trained peer support workers who work alongside the seven other members of staff. The workers are paid up to the therapeutic earnings limit. Their role is to be available to service users attending the centre, accompanying them on trips and participating in group activities, but also offering one-to-one support if needed. The peer support workers also run specific groups – a mother and child group and a women's group – and organise Tapestry, the centre's social events calendar.

Zena Palk is one of the peer support workers. She has both physical disabilities and mental health problems, and says working part-time at Resource helps her manage her own mental health. Some peer support workers have moved on to get paid work in other organisations. Trust is one of the key, unique elements of peer support, she says.

'I think people will talk to us more because we have lived experience. If they ask you, you can share a bit about yourself and how you coped with things. That helps build trust; otherwise it's an unequal relationship, like it is with professionals. I know I would have benefited if there had been peer support workers on the ward when I was in hospital. You want to talk to staff but there are so few of them and they are too busy walking round with a clipboard checking people are on the ward. Peer support workers could do activities with the patients and help them when they are first admitted to show them the ropes – basic things staff don't have time for. There are so many possibilities if there was only more money.'

One of the best known peer mental health services is the Leeds Survivor Led Crisis Service, which opened in 1999. It runs a daily crisis helpline and a weekend drop-in 'sanctuary'. It also organises a weekly Thursday afternoon social group. The service is staffed by 22 paid workers and 35 volunteers, who operate the helpline. Applicants for paid posts must have personal experience of emotional distress and preferably also

Lived Experience

A new report just published by the mental health charity Together: Working for Wellbeing sets out the benefits of peer support and the challenges faced by service users pioneering this approach.

In the foreword to the report, Rachel Perkins, Mind Champion of the Year 2010 and a pioneer in the recovery approach in the UK, writes: 'Peer support is based on mutuality and a shared journey of discovery... This is a relationship that empowers each to grow within and beyond what has happened and to find a new sense of self, meaning, value and purpose in life.'

Lived Experience Leading the Way shows that peer support has very clear benefits – individual, social and economic. It reports evaluations of peer support programmes worldwide (peer support is much more developed in North America, Australia and New Zealand). These show that service users are more likely to be in work or education; are able to cope better with their symptoms; have a better social life; make less use of mental health services; are less likely to be admitted to hospital and are discharged earlier. This all amounts to a better quality of life in general and considerable savings in spending on mental health treatment and other health and social care costs to the economy.

The report is free to download from www.together-uk.org

experience of using mental health services. They have never had any difficulty recruiting staff. The helpline takes 5000 calls a year, and Dial House – a three-bed house in a residential street – receives 1000 visits. Most of its funding – it has an annual turnover of £376,000 – comes from the local PCT (NHS Leeds) and Leeds City Council, through a service level agreement.

But, says manager Fiona Venner, it has not been an easy journey and they can't afford to rest on their achievements. 'We've survived by providing an excellent service that is highly respected by the people who use it. But we have had to over-

achieve to win this recognition. To succeed at this you have to provide a fantastic service, and you have to disseminate the evidence that you are a cost-effective option.'

Setting up a similar service now would be much harder, she warns. 'We are really well evidenced but we haven't been able to get the funding we need to expand. There is no new money in the system right now, and everyone is fighting to keep hold of the money they have got.'

Sadly, another pioneering peer-run crisis service, Kaya House in Barnet, north London, has not survived. It was forced to close its doors in February after Barnet Council withdrew its funding. Set up by the user organisation Barnet Voice in 2006, initially with grant funding from the Big Lottery and the Tudor Trust and from the council's Supporting People monies, the four-bed house offered residential crisis support at weekends.

'We were a bit naive,' says Elsie Lyons, co-ordinator of Barnet Voice. 'We knew we were running a good service, everyone said we were running a good service, and we thought this would carry us through, but it didn't. You need to be sure your project fits with your commissioner's overall strategic direction and you need to be very clear about what evidence they will expect from you to demonstrate how you contribute to the local health and social care economy. Our PCT and the council wanted proof that Kaya House reduced the call on their health and social care budgets and they felt we hadn't produced that clear evidence.'

Berkshire Healthcare NHS Foundation Trust is one of the few NHS trusts that are developing peer support on acute inpatient wards. Gwen Bonner, nurse consultant for inpatient services in East Berkshire, says: 'At the end of the day, somebody who has been through inpatient experience is an expert on being on an inpatient ward and they bring something very unique to the work.'

Ruth Le Goff was herself a patient on one of the trust's adult acute wards and now leads a weekly arts programme, which she devised, on ward 10 at Wexham Park Hospital in Slough. It took over two years to get the backing of the medical and nursing staff, agree protocols, set up a support structure, develop a volunteer contract (Ruth has specifically said she does not want to be paid as she feels this would compromise her independence), and get round the concerns of the occupational health department. Ruth always has two members of staff working with her and receives supervision both from her own therapist and from the trust. 'The key issue is safety – Ruth's and that of the patients. We are possibly overdoing it in terms of supervision but we want to be sure she has that support,' says Gwen.

The feedback has been so positive that Gwen is now rolling out the same structure to support the introduction of peer support workers on two other acute wards. 'Ideally we would have a large pool of peer workers going onto the wards but we want to see how it goes. We don't want to set us all up to fail,' she says.

'The beauty of it is that the people I see recognise I have been there too and it gives them hope that the terrible experiences they are feeling can be left behind,' Ruth believes.

Together currently facilitates a national 'Peer to Peer' group of user-led organisations offering peer support. Says Elina Stamou, Together's peer support development manager: 'We think the new strategic environment is a great opportunity for peer support, but it is also a very challenging time because of limited resources.



Fiona Venner, manager of the Leeds Survivor Led Crisis Service, with staff and visitors at Dial House
Photo © John Houlihan

Commissioners are nervous about taking a risk on something new. However, as our report demonstrates [see box on left], provided that it is developed and run properly, peer support can be extremely effective and can deliver high quality outcomes efficiently. We see it every day in our work and that of our partners.'

Peter Beresford chairs the service user-run organisation, network and think tank Shaping Our Lives. He has grown impatient with the constant demand for hard evidence that peer support 'works'. 'I try not to get angry about this but it is an issue that we have watched for years. There have been minimal amounts happening to make mainstream something that would make a major difference for the good in mental health policy and provision. It is a bad joke that the coalition government criticises statism and talks up people doing it for themselves and the Big Society yet, in percentage terms, so far only about one per cent of services are provided by peer providers – this must change.'

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

Southwark Mind User Council

Southwark Mind User Council (SMUC) is one of the projects run by Southwark Mind, a user-run and user-led organisation. SMUC is funded by the local PCT. Its role is to ensure that mental health service users in the London borough of Southwark have a genuine say in how their mental health services are organised and delivered by providing a formal structure for representation and consultation with the local commissioners and providers.

SMUC employs a total of 17 workers to liaise with and attend the meetings of mental health service user groups and forums in the community, and to visit the inpatient wards at the local Maudsley psychiatric hospital. These outreach workers come together at the SMUC monthly meetings to report back on issues and concerns raised by these groups and forums.

The monthly SMUC meetings are also attended by senior managers from the local mental health trust, local authority and PCT, as well as other key stakeholders, such as the local advocacy service. The meeting is in two parts: the first part is a closed session where the workers report back on their meetings with local groups and discuss what action needs to be taken; the second is an open session where anyone who uses local mental health services can raise issues directly with the providers and commissioners and the NHS and local authority can report back on action taken in response to concerns.

SMUC also has two seats on the PCT Mental Health Partnership Board, which is responsible for strategic planning and commissioning mental health services across the borough, and takes part in trust, PCT and local authority consultations on changes to local services that will affect service users.

Its other, very important role is campaigning to protect and improve services. For example, SMUC was very involved in a high profile campaign to save the Emergency Clinic, a walk-in crisis clinic at the Maudsley Hospital, and continues to campaign for improvements to the emergency service that replaced it. It also successfully co-ordinated a campaign to ensure local service users received Freedom travel passes.

info@southwarkmind.org.uk
020 7358 7030
www.southwarkmind.org.uk

Voice of Service Users

Voice of Service Users is an active, long-standing service user involvement group based in Scunthorpe. Its aim is to promote user involvement in local mental health services and to provide a voice for people who use mental health services in North Lincolnshire.

Voice shares an office base with Scunthorpe Mind, although it is independently funded by the local PCT. It employs one full-time worker and has about 70 members, of whom 25 are actively involved. Most of its members are people who are, or have been using mental health services. Its work includes involvement in the design and development of a new mental health unit in Scunthorpe, monitoring standards of local services (it used to be funded by the PCT to provide user-focused monitoring to the local trust, and hopes to revive this), and staff training and recruitment. It recently represented local service users in the



Sheena, a member of Voice, presents a petition to No 10 Downing Street during the general election, as part of a campaign organised by the national mental health charity Rethink

consultation on the PCT's new commissioning strategy for mental health services. It is also active in national campaigns around mental health and stigma, and has good links with its local MPs.

Voice also offers peer support. It facilitates a Wellness Recovery Action Planning group at a local mental health centre, which is funded by the Rotherham, Doncaster and South Humber NHS Foundation Trust and supported by workers from the community mental health team. This group is only open to people referred through the statutory mental health service but Voice hopes to be able to set up an independent group as well, which would be open to self-referrals.

Voice also organises social trips and activities and provides a place where people with mental health problems can meet and make friends and get help and advice and support. It has a well-used website with information and advice about mental health and local services and events.

www.voiceofserviceusers.co.uk
01724 858 343
voicesum@yahoo.co.uk

Bristol Survivors' Network

Bristol Survivors' Network is a self advocacy group for people who define themselves as survivors of the mental health system or survivors of mental health difficulties. The organisation was set up to enable support around a variety of issues – information gathering, training and campaigning to change mental health services for the better.

The history of Bristol Survivors' Network originates in the early 1980s, and a number of the early members were members of Survivors Speak Out. BSN does not directly provide any services although monthly daytime social meetings are set up to provide peer support and break down isolation. People join by forwarding a contact address or email and there is no charge. Evening business meetings are held once a month and are open to all survivors and service users.

Members of BSN attend a number of groups in Bristol, including SURG (the Service User Reference Group) and the Local Implementation Team (LIT) for mental health. A newsletter is sent out quarterly with details of meetings, training opportunities, campaigns, support groups and new developments in the wider mental health arena.

BSN has worked on the development of a crisis house, a voluntary sector project that opened in Bristol in January 2010. They campaigned successfully to prevent the closure of Clifton Ward, one of the acute wards in Southmead Hospital. They have also worked on the development of new services.

Bristol Survivors' Network has always been a user organisation. In recent years they have refused grant funding because this funding had strings attached, such as intrusive monitoring, that could have compromised their independence. BSN's running costs are extremely low – the main costs are room rental to Bristol Mind and administration costs to post out the newsletter – and at present they are running on money from various sources that has been accumulated over the years.

bsn@bristolmind.org.uk
0775 856 0987

The Expert Forum

The Expert Forum is a group of mental health service users in Birmingham that emerged from Birmingham City Council's mental health day services modernisation programme.

The forum comprises 12 members, nine of whom are service users and all of whom either represent a user-led group or organisation and/or have knowledge and expertise in setting up and running user-led groups.

The modernisation of the city's day services has resulted in the closure of the traditional day centres and greater use (with the support of a team of support, time and recovery (STaR) workers) of mainstream, community-based health, leisure and education services. It has also led to more investment in user-run and user-led groups where people can get (and give) peer support and enjoy social activities. This shift was accomplished over three years, in close consultation with local service users and carers, some of whom are now members of the forum.

The role of the forum is to support and advise other service users on how to set up their own groups and organisations. It also advises and supports three service user steering groups – one for each of the three PCTs covering Birmingham – that support the development of service user groups within their patch.

The Expert Forum (so called because of the expertise they have built up by experience) can advise on issues like writing a constitution, funding and other practical issues. They are currently working on what they provisionally call a Rough Guide to Doing It Yourself – a toolkit to help service users set up their own peer support, activity and social groups. The forum is currently funded through the day services modernisation programme but is aiming to become independent.

Contact Jane Thakoordin, project manager 0121 657 6604
Jane.m.thakoordin@birmingham.gov.uk



Viewpoint staff

Viewpoint, Hertfordshire

Viewpoint is a service user involvement charity based in Hertfordshire. It started as a project run by the local Mind associations and gained independent status as a service user led charity in 2003. Its aim is to enable the views and expertise of people who use or have used mental health and drug and alcohol services in Hertfordshire to inform and promote improvements in local service provision. It employs eight members of staff and has 600 members, the majority of whom are mental health service users.

Viewpoint is core funded and commissioned by Hertfordshire County Council. Forums are held across the county to gather service users' views, which are fed to the appropriate service providers. Viewpoint members also contribute to focus and steering groups and consultations held by Hertfordshire Partnership NHS Foundation Trust (HPFT) and the joint health and social care commissioning team (JCT). For example, service users have designed a questionnaire about day services, facilitated peer-to-peer reviews of services and developed a county-wide communications strategy for the JCT. Viewpoint members are also involved in HPFT staff recruitment and its policy reviews. Viewpoint also works with local mental health and drug and alcohol agencies.

In addition to this consultation and user involvement work, Viewpoint provides confidence building and presentation skills training for service users, who then help lead its training courses for the police, mental health professionals, clergy, schools and drug and alcohol agencies. Viewpoint has produced a DVD, Dealing with Mental Illness, as a training tool for employers.

As a result of their involvement, some service users have developed confidence to go back into mainstream paid employment.

A newsletter is produced seasonally, with service users' stories of recovery, artwork and poetry and information about sources of support and opportunities to get involved. Copies are sent to members and to every mental health and drug and alcohol service provider in the county, GPs, libraries and Citizens Advice Bureaux. It is also available online.

www.hertsviewpoint.co.uk
t: 01707 328014
e: info@hertsviewpoint.co.uk

JOIN US!

NSUN's aims are to:

- facilitate active links between service user/survivor groups and individuals
- build capacity for service user/survivor groups
- broker and facilitate access to service users/survivors for purposes of influencing and informing policy-makers and planners.

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