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
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 WSH 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.

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 or dorothygould.org.uk@hotmail.co.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.

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 family commitments. Fran can be reached on fran.singer@nsun.org.uk tel 0845 602 0779 or 0207 820 8982.
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 movement 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.g. MIND, 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 helps her manage her overall 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 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 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 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. ‘The key issue is money,’ she says. ‘When we started it was hard to get funding. We were told we could only do this if we worked with 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 beauty of it is you get to know people who are different. We are part of the same team but are from different backgrounds. We treat each other as equals.’

The feedback has been so positive that it is now providing this support to other wards. ‘We had 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 challenge now is to develop the service and to embed it in the wider system. ‘We can’t do it on our own,’ says Ruth. ‘We need to develop other projects with the same structure to support the introduction of peer support workers on two other adult wards. We need to demonstrate that it works and that we need funding to expand.’
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 Day 15 crisis 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, 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 is 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 users in the 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 Humberside NHS Foundation Trust and supported by workers from the community mental health team. This group is open only 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 tips 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.

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

Bristol Survivors’ Network
Bristol Survivors’ Network is a self advocacy group for people who have used mental health services. 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 and email and there is no charge. Every month of 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 Survivors Speak Out 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 was 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 9897

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 service 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 local 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 PCT’s covering Birmingham – that support the development of service user groups within their patch.

The Expert Forum (so called because of the expertise they have) meets on a regular basis, usually two nights a month. It is an evening business meeting that anyone can attend. There is no charge for attending these meetings. There is food and refreshments provided.

The Expert Forum also produces a newsletter, Viewpoint, which is aimed at all survivors and service users. The newsletter contains stories of people with mental illness, as a training tool for employers.

www.viewpointmind.org.uk
07758569897

Survivors Speak Out
Survivors Speak Out (also known as SPO) is a group of service users who have used mental health services in Hertfordshire. It started as a project run by the local Mind associations and gained independent status as a service user-led organisation in 2003. Its aim is to contact 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.

Survivors Speak Out 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.

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 activities. It is available online.

http://www.hertsviewpoint.co.uk
01707 328014
e: info@hertsviewpoint.co.uk

GOOD PRACTICE

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 organisation in 2003. Its aim is to contact 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.

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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)..........................................................................................................................................................................................................................................................................................................................................................................................................................................................................................................................................................................................
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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