nsun para di

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NSUN joined the TUC protest against public spending cuts in London in March this year

NSUN WINS PRAISE FROM FUNDERS

NSUN has been given a huge vote of confidence by its funders Comic Relief and the Tudor Trust and has been encouraged to apply for further funding after the current five-year grant runs out in March 2012.

Comic Relief recently completed a formal evaluation of NSUN's first four years. The evaluation praises NSUN's 'notable successes' in its primary aim to support service users to be more involved in the planning and development of mental health and social care services and policy. It says that NSUN is still very much needed by service user groups, particularly in the face of the radical changes ahead in how services are commissioned and provided, and the deep public spending cuts: 'Many service user groups are extremely fragile. NSUN's role as a knowledge, capacity and capability broker has the potential to help groups improve their resilience during this uncertain period and ready themselves for opportunities that are likely to emerge.'

The report says the key challenges for NSUN are to expand its membership and continue to focus on capacity building work with service users and user groups, and develop links between service user groups and organisations. It also highlights the increased importance of NSUN's role as a platform for ensuring service users can make their voices heard to providers, commissioners and policy makers, now that NMHDU has been abolished.

Peter Argall, UK Learning and Development Manager at Comic Relief, said the evaluation showed that NSUN is clearly filling an important gap. 'The first four years were not without difficulties, but NSUN has achieved a great deal. You can already see the added value it has given to the voice of mental health survivors and users.'

NEWS ROUND-UP

NSUN LAUNCHES NEW FIVE-YEAR PLAN

NSUN has developed a five-year plan 2011–2016 setting out its main strategic objectives in five key areas. These are communications, membership recruitment and management, engagement and capacity building (specifically BME and forensic service user groups), partnership working, and involvement and influencing.

All are aimed at the same overall objective: to increase NSUN membership and thereby add to the strength and validity of the user voice and its potential to influence decision-making at every level.

The strategic plan sets out the achievements to date. NSUN has successfully established itself as an independent organisation. It has increased its membership by 200% in 20 months, to a new total of 1050. It has relaunched and improved its website, offering new networking facilities and capacity to members. It has established a respected profile at national level, including membership of the Department of Health's strategic partnership for mental health. It has built robust partnerships with ally organisations in mental health and disability rights. It has completed a number of important projects, including the Dancing to Our Own Tunes report on BME service user involvement and the survey of user involvement in forensic mental health services.

The five-year plan puts numbers to NSUN's objectives. Targets are, by 2016, to expand NSUN's communications 'reach' to 38,400 groups and individuals; to increase its membership to 12,800; to establish nine regional networks, including the north east and south east networks already in place; to create ten new strategic partnerships with organisations that share its concerns, while strengthening existing alliances, and to support the engagement of 1500 service users nationwide in policy development and strategic decision-making.

The five-year plan was informed by feedback from membership surveys, which consistency identify policy and campaign work and lobbying and talking to government as key priorities for NSUN, alongside the need to protect and strengthen the independent user voice.

'By building our membership to a critical mass, we will be maximising our influence and the strength of our voice,' says NSUN chair Susan Haworth.'We've set ourselves tough goals and high targets, but we have made enormous progress in a very short space of time and have every confidence we can achieve our aims.'

The five year plan can be downloaded from the NSUN website at www.nsun.org.uk

New NSUN posts

NSUN has been awarded funding by the Esmée Fairbairn Foundation to employ a full-time communications and engagement officer and a parttime information officer. The funding is for three years and will allow NSUN to improve and develop its internal and external communications, website, membership engagement and information services. The new staff will be in post by the end of the year.

'These new staff will make a big difference to the support we can offer members and our work to ensure the voices of service users and their concerns are heard clearly at national level,' NSUN chair Susan Haworth said.

WHO WE ARE

There are six of us on NSUN's board of trustees. Susan Haworth (chair) Carolyn Anderson Alisdair Cameron Joyce Kallevik (treasurer) Kath Lovell Dominic Makuvachuma-Walker Clare Ockwell

We would like to say a huge thank you to Tina Coldham, who stepped down as chair in January 2011. Tina

played a central role in setting up NSUN and led us through to independence from our host organisation Together Working for Wellbeing.

We also have six 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, NIP co-ordinators; Soka Kapundu, part-time operational accountant, and Shoket Ali, part-time IT support officer. We are also supported by five wonderful volunteers: Stephanie Taylor-King, Joe Kelly, Sarah Newton, Stephanie McKinley and Jo Josh.

NEWS ROUND-UP

North west network

NSUN is currently talking to service user and carer groups in the north west about maintaining a regional network following the closure of Collective Voice North West (CVNW). CVNW was funded for 18 months by Rethink and the University of Central Lancashire, but the funding ran out in March this year.

NSUN has surveyed CVNW representatives and found strong support across the region for the continuation of the network and a positive perception that NSUN has the relevant experience and infrastructure to support and develop it.

'We have applied for funding and are talking to local groups about what they feel would be appropriate. Ideally, a local group would take on a co-ordination role,' Sarah Yiannoullou, NSUN manager, said.

London trainer survey

NSUN is conducting a survey of service user involvement in mental health training across the London region. The aim of the survey is to assess levels of need for and use of service user trainers, if service users are being paid for this work, and how much, if organisations have policies for employing service users in training, and what support they provide.

'Most organisations who ask service users to provide training don't have a policy. Our idea is to set up a network, if that is what service user trainers in the region want, so we can agree standards, policies and pay rates for user involvement in training and be taken seriously as professionals,' says Stephanie McKinley, who has been seconded by the South London and Maudsley NHS Foundation Trust to work on the project with NSUN. NSUN has applied for funding for a London network co-ordinator post.

• National Involvement Partnership (NIP)



NSUN is continuing to support the development of NIP as a national user involvement project, following the closure of the National Mental Health Development Unit (NMHDU). NIP was originally set up to work within NMHDU. NIP's new work includes establishing a values-based framework of national standards for involvement and good practice known as PPPI (Process, Practice, Purpose and Impact), which is led by people using services and by carers. NIP is also collecting together the wealth of involvement and engagement products and policies currently available as a resource for NSUN members. In addition NIP has put together a wide-ranging portfolio of mental health training programmes that it offers itself or can contract from other providers. For further information about NIP email philip.partridge@nsun.org.uk or fran.singer@nsun.org.uk

Leadership training

The North East Together Service User and Carer Network has just completed a seven-month 'Leadership for Users, Carers and Advocates' course run with the North East Mental Health Development Unit (NEMDHU) and the two local mental health trusts. The programme was funded for 16 places, but 33 people came to the induction day.'We didn't want to turn anyone away so we re-profiled the course so they could all come,' said Paul Johnson, programme lead at NEMDHU.'The course benefits participants personally and it's also very useful for health and social care providers because it increases the competence, confidence and capacity of individuals to participate in service improvement.'

In the south east, NSUN ran a four-day 'Champions' course for 15 participants in May and June with Canterbury and District Mental Health Forum, to develop leadership and networking skills and personal confidence. The course included topics such as managing meetings, talking to the media, making presentations, and also one-to-one coaching to help people overcome personal blocks to service user involvement work.



LEADERSHIP AND INFLUENCE

COMMISSIONING CHAOS Voluntary sector

The government's plans to change the way health services are commissioned are already having an impact on mental health service user groups. Some of the difficulties are around the lack of clarity about patient and carer involvement in the new structures, and who will be responsible for commissioning mental health services. But there is a well-founded fear that mental health service users and their needs will be elbowed to the sidelines while other, more vocal patient groups grab the seats on strategic planning forums. Catherine Jackson reports.

Under the Government's Health and Social Care Bill, by 2013 most health services will be commissioned by new clinical commissioning groups (CCGs), led by GPs with (following the recent amendments to the Bill) input also from hospital doctors and nurses. The Bill hasn't yet been passed but the changes are already being introduced. PCTs are being 'clustered' into fewer, larger commissioning groups; PCT mental health commissioners are losing their jobs, or leaving before they are made redundant, and 'pathfinder' CCGs are beginning to flex their muscles and decide where they want to spend NHS money.

Patient and public involvement in the new structures appears to be minimal. New Health and Wellbeing Boards (HWBs) will be established in every local authority area, with responsibility for assessing local health and wellbeing needs and drawing up strategic plans for how these needs will be met. The CCGs will have to commission services to meet the needs identified in the strategic plan. Currently there are two routes for patient and carer groups to influence health service planning and commissioning. There will be a single seat for a local HealthWatch representation on the Health and Wellbeing Boards (local HealthWatch groups are replacing the current Local Involvement Networks (LINks)). This means there will be just one patient/carer seat representing every health interest group in the area covered by the Health and Wellbeing Board. CCG Commissioning Boards are also required to include at least two lay representatives, one specifically to champion patient and public involvement.

Mental health service users and service user-led groups have two main concerns: how to make sure their views are still heard at strategic planning and commissioning levels, and whether the peer-led services they offer will continued to be commissioned by the new, GP-dominated CCGs.

Sidelined

Negative effects are already being reported. NSUN member organisations the length and breadth of England are mourning the loss of valued relationships with local PCT mental health commissioning leads, and wondering what is going to replace them.

Says Catherine Ingram, chief executive of Derbyshire Voice:'It's chaotic. We are dealing with commissioners who are the last ones left standing, who don't understand about mental health and haven't got that history of working with service users. There's no organisational memory or knowledge of what is happening. The structures for accountability are very unclear and we don't know who is making the decisions. Locally, the GPs are starting to come to strategic planning meetings so hopefully they are listening and learning.'

The King's Fund recently published a report with the NCVO on the implications of the NHS reforms for community and voluntary sector (CVS) organisations providing services. The report helpfully explores the best-case and worst-case scenarios of GP-led commissioning.

Fiona Sheil, public services officer at NCVO and one of the report's co-authors, offers this advice to mental health service user groups hoping to win contracts to provide peer support services:'First, when you are talking to the GP you need to be able to articulate what you do and what is unique about what you do, very simply and in financial terms. Give them human interest stories – GPs relate to the human angle. Second, we are going to see far more use of integrated care pathways and Payment by Results. So you need to know what the mental health pathway is locally and where the crisis points are. Work out how what you provide can contribute to tackling those crisis points, and if you can provide a complete care package by collaborating with other CVS organisations. Third, GPs will want to procure on a huge scale because that is seen as more efficient and less risk. Small groups need to think about forming consortia to bid for contracts. But you have to be able to demonstrate the impact of what you offer and your ability to deliver it.'

The Voluntary and Community Sector in Health: Implications of the Proposed NHS Reforms, by Natasha Curry, Claire Mundle, Fiona Sheil and Lisa Weaks. Free to download from the King's Fund at www.kingsfund.org.uk

Her concerns are echoed by Lorien Barber, director of North Staffs User Group. 'We are lucky in that I chair the local mental health partnership board for Stoke, so we can still ask questions and ensure we aren't ignored, but the pace of change is so fast. While there are people in post who understand us and what we do, we are reasonably confident we will carry on, but every time I go to a meeting with the commissioners, another person has left.'

Lorien is worried that there won't be a designated place for mental health service users within the new strategic planning forums and that mental health issues will slide down the agenda. "I've been told the Health and Wellbeing Board will replace the partnership board but it will meet just four times a year – there'll be no space to go into issues in detail because the agenda will be huge."

Catherine Ingram says mental health service users are already being marginalised in Derbyshire.'People have had very negative experiences of LINks meetings in the past. My worry is that HealthWatch will be the same – dominated by the bigger, more vocal groups and by people who are much more confident and able to deal with these kinds of meetings. You can encourage and

LEADERSHIP AND INFLUENCE



Protesters at the Mad Pride march against cuts in benefits and mental health services in October 2010 Photo credit: Mad Pride

support mental health service users to go to these meetings, but if it's an uncomfortable experience they won't go again, and you can't blame them.'

GP commissioners

Service user groups are also wondering who they should be talking to in the new clinical commissioning groups. There are currently no clear pathways for talking directly to the new GP commissioners, other than the panels that some GP surgeries have in place for patient feedback. Yet, as a recent Rethink survey showed, the overwhelming majority of GPs admit to knowing very little about mental health.

In Newcastle, where a number of 'pathfinder' CCGs are already operating, Alisdair Cameron, team leader at the user involvement organisation Launchpad, has grave doubts about the willingness of GPs even to listen to mental health service users.'Some GPs know the score and value service user involvement, but the ones that step forward earliest are those with the most misplaced belief that they know it all and can do it all. I have lost count of the times I have heard GPs saying they deal with 99% of mental health problems in their surgeries and know everything there is to know about the issues. The trouble is, they have a completely different definition of mental health to us. And GP panels are like a customer satisfaction focus group – there's no involvement in planning and design of services, and there's no scrutiny. Involvement will be generic and not as we know it – it'll be consumer satisfaction type stuff.

'I don't think GP commissioners see mental health service user involvement as important. They say, "Why not a diabetes involvement group, then?" They don't understand the important difference – mental health care involves civil liberties, and the treatments have the weakest evidence base.'

Diane Woods is associate director of commissioning for mental health and learning disabilities at NHS Surrey. She too deplores the 'brain drain' of mental health leads leaving their posts at PCTs, and taking their knowledge with them.'There are legacy documents being developed in PCTs to try to mitigate that risk, but it's the relationships that are key – the people who have formed these relationships may not be involved in the future, so what service users have to offer could be lost.'

But she says GPs do have an understanding of mental health and local needs, precisely because they see so many people in their surgeries with mental health problems, and that they are keen to improve mental health services locally.'For GPs to commission well they need both the larger critical mass of block commissioning and local sensitivity. It's that interface between the local and the large that provides opportunities for small service user-led groups. But there isn't a critical mass of service user influence at individual GP practice level, and that is where difficulties are for service users in influencing commissioning decisions.'

In Coventry, service user involvement group AIMHS has adopted a new tactic to try to reach GPs. Says Andy Collis, service manager: 'We've been doing specific small group training with service user representatives so they can go to their own GP patient panel meetings and talk about collective issues. It's the only way we can think of to be proactive and raise awareness of mental health issues among GPs, some of whom will be on the CCGs. GPs do have a statutory duty to consult their patients and we are going to try to take the message to them.'

In East Kent, where a number of pathfinder CCGs are also already operating, Angela Harrison of Shepway Open Forum says she has been surprised by the willingness of local GPs to listen to the views of mental health service users.'Shepway GPs organised a training evening for GPs on mental health a few months ago. It was structured like speed dating – we sat at tables and the GPs moved from one group to the next. There were about 39 GPs. The GPs are now making more use of local service user groups and organisations.'

As Catherine Ingram points out, mental health service users and user organisations could be very helpful to CCGs, if only they would listen. She has an open mind about GPs' knowledge of mental health issues. 'We do have some very forward-thinking GPs who share some of our frustrations about mental health service provision locally. My hope is that they will identify the gaps we know exist and sort them out. That is my optimistic side. We could help them so much if they had the capacity and time to listen to the people who are receiving these services.'

GOOD PRACTICE

NSUN MEMBERS DO IT FOR OURSELVES

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

Impact, Bedfordshire

Impact MH is an independent charity based in Bedfordshire and Luton that works to improve the quality and delivery of statutory and voluntary sector mental health services by engaging service users in their planning, development, monitoring and evaluation. It employs six staff, all of whom have experience of mental ill health and mental distress, and also offers opportunities to volunteers to work with them.

The organisation is open to anyone with experience of mental health problems. It currently has around 120 members. It facilitates and hosts meetings with inpatients in the three acute psychiatric units covering the area and the local low secure forensic unit, and offers a service user consultancy service to commissioners and mental health service providers. Says Déanne Clark, chief executive: 'Our vision is to build and sustain meaningful channels of communication and partnerships between mental health service users, commissioners, mental health service providers and the wider community.'

Impact MH was hosted by Bedfordshire and Luton Mind for its first five years. It became a charity in its own right in April 2010. It is primarily funded by NHS Bedfordshire and NHS Luton PCTs, but also receives some local authority funding to support service user involvement at strategic meetings and has recently been awarded a significant grant from Comic Relief. www.impactmh.org.uk tel: 01582 611 079



The Two-Way Street, Bristol

The Two Way Street was founded six years ago. It is user and carer led and run, and targeted primarily at the black African and Caribbean community in Bristol. Its aim is to provide information to the BME community and BME service users and carers about the mental health system so they are able to get the help and treatment they need. It also represents BME service users and carers at strategic planning levels. It is the only black mental health organisation in Bristol.

TTWS is currently staffed by executive director Rachel Barclay and eight volunteers. It is a social firm and a limited company and is in the process of becoming a Community Interest Company. It runs regular drop-in 'surgeries' from community venues across the city, offering advice, support, tea and company to service users and carers. It also offers a large range of training courses for service users and carers and for mental health professionals. Last year it set up a Cultural Communications project to provide a channel of communication between BME service users and carers and the PCT, but the PCT funding for this ended in April 2011.

Tanzi (not her real name) has been coming to TTWS for over a year and now works there as a volunteer: 'The support here has been brilliant. I have learned to face up to my demons and come on so much and met so many people. I think anyone who has been in hospital should definitely come here. It really does assist in your recovery.'

http://www.thetwowaystreet.org.uk tel: 0117 955 8599



Stockport User-Friendly Forum (STUFF)

STUFF was founded in 1999 by eight mental health service users who 'wanted a voice' and to make a difference in Stockport. It is a voluntary, service user-led mental health support group. It has no paid members of staff and is run by a small management committee and its members. It receives a small grant from Stockport PCT, and also raises money for its activities by providing training to external organisations.

STUFF runs a weekly afternoon drop-in at the mental health unit of Stepping Hill Hospital in Stockport, which is open to anyone – inpatients, outpatients and service users in the community. It also stocks several racks of leaflets at the hospital with up-to-date information on mental health topics, local support groups and social activities. Once a month it organises a mental health forum at the Well Being Centre in Stockport, with invited speakers and a 'STUFF buffet'.

In addition, STUFF acts as a two-way channel of communication between service users and local mental health service providers.

STUFF is a membership organisation. This is a fairly recent change; committee members thought users would have a greater sense of ownership they were members, and also it provides a structure for people to have a say in what STUFF does. Membership only costs £5 a year.

In February, the group won the Stockport Borough Council's 'Proud of Stockport Volunteer Champion of the Year Award'. 'That was a real accolade for us,' says committee member Margaret Hall.

http://stockportuserfriendlyforum.wordpress.com

GOOD PRACTICE

The Tamarind Centre

The Tamarind Centre was founded in Coventry in 1989. It is a registered charity and limited company and provides a range of support services to African Caribbean and Asian people with mental health problems.

The centre employs four members of staff, and four freelance counsellors. Volunteers, including people who have used Tamarind's services, provide befriending and one-to-one peer support, and help out with office administration and group activities.

The centre is open daily and has about 150 people on its books at any one time. People can self-refer or are referred by mental health services and GPs. Qualified counsellors offer one-to-one sessions in English, Patois, Punjabi and Hindi. The centre also runs a wide range of drop-in groups and activities. The mental health support includes advocacy, support at mental health tribunals and CPA reviews, and individually tailored packages of community care. Centre staff also visit the local psychiatric hospital wards to offer outreach to African Caribbean and Asian patients. An Asian ladies group meets twice a week at the centre, and there is a weekly Caribbean men's group, and a monthly carers group. The centre also offers cultural awareness training to the voluntary sector and statutory and independent sector agencies.

Funding comes mainly from the local PCT and local authority, through a service level agreement, supplemented by grants and other one-off income streams. 'We support people as they are when they come through the door, whatever their needs. People need the choice to see someone to whom they can relate culturally,' says Marcia Jarrett, centre manager. www.tamarindcentre.co.uk 0247 622 7712



Mad Pride

Mad Pride is an international civil rights movement, a UK national campaign group and a celebration of madness, all rolled into one.

There are Mad Pride organisations in countries all over the world. Mad Pride was formed in the UK in about 1998. It is based very loosely on Gay Pride, and takes the same civil rights approach of 'reclaiming' a label with a negative value (ie.'mad') and turning it around to give it a positive spin. Many of its founding members were members of other mental health survivor protest and activist groups, such as Survivors Speak Out.

Over the years Mad Pride and its 'provisional' wing Reclaim Bedlam have organised numerous campaigns and protests.

They include a protest at the service held in St Paul's Cathedral in 1997 to celebrate the 750th anniversary of the founding of the Bethlem Hospital. There was national outrage when Mad Pride 'reclaimed' Sir Winston Churchill's statue in Parliament Square at its rally to protest against the passing of the Mental Health Act 2007. Most recently it organised a huge demo against the benefits and mental health service cuts in London in October 2010, from which emerged the Mental Health Resistance Network, which is continuing the campaign. Alongside there have been numerous gigs, fundraising events and other impromptu local protests and campaigns.

'Basically, we encourage people to take the name and do things in their own area,' says Mad Pride spokesman Mark Roberts. 'We've had some setbacks but we keep coming back. Mad Pride is really just a group of people who like working together.' www.madpride.org.uk



Changes, Stoke-on-Trent

Changes was founded in 1988, became a registered charity in 1994, and is currently in the process of becoming a Community Interest Company (CIC). It provides community-based, openaccess, open ended, recovery-focused support to people in mental distress across North Staffordshire and East Staffordshire.

It has 35 full-time employees, 33 of whom have personal experience of mental distress. Based in Stoke-on-Trent, with centres in Burton upon Trent and Uttoxeter, it offers recovery and wellbeing support on two levels: free, open-ended, open access, weekly mutual support groups led by trained, qualified co-ordinators, and a range of time-limited recovery and wellbeing workshops. There are support groups for young people, working age adults and older people; new 'taster' groups for BME people have just been introduced at its East Staffordshire centres and it also runs mental wellbeing groups in prisons.

Changes is funded through service level agreements with its local PCTs and mental health trusts. Some 1000 people join its groups and workshops in a year. All its workshops and support groups are based on Changes' own 12-step structured approach to recovery. It also provides training and support to people who want to work with Changes as volunteers. 'Some of our employees hadn't been in paid work for years and are now working full-time for us and managing their mental health. These are all people who have achieved their potential and are now working to help others achieve theirs,' says co-director Barbara Wain.

www.changes.org.uk tel: 01782 206 422

JOIN US!

NSUN's aims are to:

- facilitate active links between service user/survivor groups and individuals;
- · build capacity for service user/survivor groups, and
- 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.

You can join online at

http://www.nsun.org.uk/membership/ 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 nar	ne (for groups/organisations only)			
	County			
Phone number		E-mail addres	s	
Website				
	nglandEast MidlandsLon SouthwestWest Midlands		Northwest 🗌	South Central 🗌
	v 🗌 Independent sector 🗌 Oth ils)		/	
	apply) ensics BME Depression ils)			Elderly 🗌 Other 🗌
	apply) r more) 🔲 Service user representati er group (100% service user led) 🗌	on (50% or less) 🗌		
Other (give details)				
Mission statement/Desc	ription			
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