



## **Independent analysis of NSUN 2011 Members' Survey**

### **Summary of the survey responses**

#### **Respondents**

107 people completed the survey.

Most of these (75 people) were individuals, not representing a group.

13 people were not yet NSUN members.

Respondents were fairly evenly spread regionally, with the most respondents (21-23 people for each) from London, the South East and the North West.

#### **Perceptions of NSUN**

68 people (77%) had a positive perception

16 neutral

2 negative

2 other (of which the comments were 'oriented towards London and 'has rather a low profile').

#### **Particular issues faced**

**(64 comments, but some people mentioned more than one issue, numbers are for numbers of times something was mentioned)**

Cuts – 16

Lack of available/appropriate services – 10

Stigma/discrimination/violation of human rights - 10

Local government/health authority attitudes/incompetence – 8

Equalities issues - 8

National government policies (e.g. Welfare Reform Bill)/attitude – 6

Personal material survival – 4

Organisations claiming to be user-led actually professionalised and bureaucratic - 2

Medication - 2

Rural isolation – 1

Tokenism – 1

#### **Quotes**

##### **Government policies/attitude and cuts**

'I have the feeling that disabled people are being targeted as 'the origin of the deficit'... I am terrified that Britain is sliding towards fascism and, if such be the case, I and my fellow mental health sufferers would be soon even more victimised than we already are.'

'Funding and continuing to support those with [mental health] problems is becoming more difficult and tied with legislation that we may have to stop supporting those with generic problems or who are not sectioned under the act. Advocacy work was intended to support all who experienced difficulty in their daily lives and support with attending appointments and understanding their rights, and assist them to access services which are now being cut.'

'Why are my needs not represented on a national footing? They're not on TV. Why is my benefit under threat? Why don't we shout louder?'

'Funding cuts are hitting service user groups particularly hard. Also extensive NHS reorganisation is having a major impact on patient care and on NHS staff morale.'

### **Stigma**

'I feel like I am part of a group targeted with hostility.'

### **What does NSUN do for you?**

**(84 comments, numbers are for times something was mentioned)**

Providing information – 65

Linking people – 18

Support/training/events/activities people can get involved in – 16

Campaigning/challenging/raising profile of issues – 14

Mutual support – 8

Feeling part of something bigger – 4

Forum for promoting own work – 4

### **Quotes**

#### **Collective voice**

'Gives me, as an individual, a much needed sense of belonging through being a member.'

'Fights collectively for my interests as a service user.'

#### **Useful information source**

'Really useful network which keeps me in touch with user involvement activities nationally which I can then pass on to the people I work with.'

'It provides invaluable info on a regular basis from a single source (info that is often unavailable elsewhere).'

'More than anything the NSUN newsletter helps to keep me up to date with news and events. It does so in a way that I can manage and find accessible especially now in the current political climate, where I find listening to the news overwhelming and depressing...I really like the way the news letter includes jobs, which I find to be positive re-inforcement....All in all it's a brilliant way of keeping informed and creating a positive identity.'

'[NSUN] gives me news, information and best of all ideas.'

### **Negative comments/suggestions for improvement**

'Provides information - occasionally mis-information.'

'There is no group in my area. I just receive an online newsletter. I tried to attend the AGM in 2011 and staff conspired to make it so hard that I gave up. I was ignored then lied to in equal measure. I was shocked and dismayed at such overt discrimination from a user-led organisation.'

(NB: this is the only overtly negative comment in the whole survey).

'Information bulletins really helpful, if a bit London centric. [There are] more things to know about in the rest of the UK, Europe and the world, from the service user perspective of course.'

### **What do you want NSUN to be doing in 1-3 years' time?**

**(82 comments, numbers are for times something was mentioned)**

More of the same – 32

More campaigning – 14

More regional reach – 14

(East, North West, Yorkshire, Midlands and Suffolk/Norfolk mentioned)

More local/on the ground support – 7

Increase membership – 6

More face to face networking opportunities – 4

Raise profile – 4

Provide/helps groups access funding - 3

More training – 3

(research, consultancy, public speaking, facilitating meetings, involving service users, leadership, campaigning mentioned)

Capacity building- 2

More equalities/human rights work – 2

Links with disability rights movement – 2

Don't criticise psychiatry, work with the government - 2

Summaries of policy documents – 1

Publications/guides on involvement - 1

Education work – 1  
User-led research - 1  
Paper newsletter – 1  
Linking re specific diagnoses – 1  
Retain/clarify user-led focus and independent identity – 1  
Work on mental health and employment – 1  
Volunteer mentors programme – 1  
Focus on Europe, not just England/UK - 1

## **Quotes**

### **More of the same/expanding existing work/regional reach**

‘Still being there, still holding organisations together, keeping them connected, and keeping everybody up to date with news etc.’

‘More of the same but with a higher profile and more consistent funding across the regions.’

‘Don’t forget to include local area support services, try to put in something about each local area in your e newsletters so that we can keep them and refer to them when needed.’

‘Be stronger in developing the network of groups and individuals nationwide, we need a good presence in every region, so that a collective voice can be mobilised on national issues.’

‘I would like to see NSUN continue what its doing but reaching out to a greater number of service users. I am continually asking other service users whether they are members, or have heard of NSUN and am disappointed to find out they haven't. In my limited experience it appears to be people who have an almost professional grasp of the health system and services who are aware of NSUN.’

‘To develop a coalition of service user organisations that have more strength in numbers to lobby decisions makers or be proactive in setting the agenda.’

‘It would be nice to see representatives within each county and a forum once a year bringing all those reps together to share information, ways to involve service users and carers etc.’

‘Now that MIND has abolished Mindlink, UKAN and Survivors Speak Out have virtually ceased to exist there is no other national voice for users and survivors.’

### **More project activity**

'Perhaps running more 'get-togethers' of people (like the highly successful AGM), maybe in regions.'

'Linking up groups dealing with similar issues, e.g. providing similar services, undertaking similar activities.'

'Would like to see more training and building larger networks of Champions across the national map.'

'Be funded to undertake more work for the Government such as systems that work that assist mentally ill people to move from benefits to work in a sensible, planned way.'

### **Higher profile**

'Have a higher profile in national debates that concern us - our voice should carry more weight than MIND, SANE or Rethink.'

'Having a stronger influencing voice rather than the government departments automatically approaching the big and not so user-focused charities.'

'I think you should ensure your flyers/leaflets get into general surgeries.'

'Have been very pleased I found you - through a random web search. Larger mental health organisations do not seem to promote you although you carry info re their campaigns etc.'

'I don't think NSUN is well known enough - it would be good to market yourselves say through all CMH teams, through psychotherapy magazines such as Therapy Today and even through Psychologies magazine.'

### **Campaigning and media work**

'The bonfire of the quangos and NHS reform has deprived most community centered mental health initiatives of funding. NSUN needs to become politically active to lobby and campaign for the resources needed to ensure that community approaches don't die out.'

'The present government seems to be mounting a propaganda campaign against vulnerable people and drip feeds the public with carefully chosen statistics which are often questionable in terms of context and are causing individuals considerable stress and anxiety. We need an informed and articulate counter to that in order to provide the voting public with an alternative perspective.'

'More needs to be done to publicise what people who have a mental illness can and have achieved.'

### **Comments about NSUN focus/ethos**

'Verify how really 'user run' are the bodies it presents as being 'user run'.'

'Not taking an anti-psychiatry stance.'

'NSUN needs to far more critical of psychiatry and government...it seems to be doing too many reviews and work for mental health care trusts and government rather than being national critical voices for service user survivors.'

'Very tempting to work with partners but must be avoided unless they are user/survivor organisations. Carer issues is difficult but avoid setting up a space for carers in NSUN. Signpost carers who are also survivors elsewhere for a carers debate.'

'I think it needs to be careful not to lose a challenging edge - not to cosy up to the government/psychiatric establishment too much.'

'Acknowledge that there are people with a wider range of views on mental health - for example those who may not identify as survivors. I am not clear whether they should be part of NSUN or whether NSUN should be narrowly focused. I guess it would be better to be the specialist organisation? I am not clear where NSUN sits in relation to organisations like Mind - there appears to be a lot of overlap between different organisations. Should NSUN be a distinct and separate organisation or look to being supported by Mind? Again I'm not sure!'

'NSUN should attempt to have clear links in the future with other minority organisations, such as LGBT groups. Preferably those organisations should also be peer led and also receive funding from sources which are not linked to the government.'

### **New ideas**

'An initiative to create a website which will tell service users the truth about the menu of available opportunities for treatment, and how these are reviewed by other service users. Become a clearing-house for independent information on the effectiveness of different treatments, as reported by service users themselves.'

'Highlight good and bad practices that members have experienced.'

'Perhaps also providing an archive (or links to) mental health related resources.'

'Offer groups signposting to others who might help them in achieving their aims or can offer expertise perhaps on a timebanking type model as we are all short of cash.'

**Is there anything NSUN needs to be doing that it is not doing currently?  
(70 comments)**

This question elicited a lot of repetition of responses from the previous question, and a number of people putting 'as above.' I think it could have been combined with the previous question. I have therefore added the very few new points made here to the results for the previous question.

### **Rating of NSUN activities**

**(70 responses)**

#### **Positive**

The top rating was given to e bulletins (54 people rating them 'very good' and 18 people 'good', nobody rating them 'poor')

The next highest rating was for the publication 'Network'.

Other activities mentioned as positive were conferences, facebook, personal support, website and campaigning (2).

#### **Negative**

Regional networking was rated 'poor' by 30 people (very good' by 5, 'good' by 16). This is an area of concern. It would be helpful to go back to the raw data to establish the region of those who found it poor.

One person commented that they had not received 'Network' and another said 'you need to be clearer about what you do'.

### **Have you ever contacted another NSUN member after hearing about them through NSUN?**

**(81 responses)**

Most people had not (77%). One person commented 'how would I do that?'

Of those who had, many helpful contacts were described, including help with events and research and links to campaigning groups.

### **Other networks**

**(81 responses)**

There were a number of responses indicating that this question was unclear and that the meaning of wider networks should have been defined. I'm not clear about the purpose of gathering information about people's involvement in other networks, without knowing more detail about what these are.

Most (70%) were part of other networks. Advantages to network membership described included:

Info/ideas sharing – 14

Reduced isolation – 7

Understanding regional variations/how others do it – 5

Economies of scale – 3

Increased publicity for work – 2

Increased confidence – 1

Disadvantages mentioned:

Some networks control people's involvement too much – 1

Conflicting agendas within networks - 1

### **Quotes**

'The sense of belonging , peer support is invaluable, seeing what others are doing and being inspired by this.'

'It can be challenging but I strongly believe the more we talk to each other the more we can present a collective voice and build ourselves as a movement.'

### **How would you rate your contact with NSUN?**

**(81 responses)**

The highest ratings went to:

Website, rated 'very good' by 31, 'poor' by only 1

E mail, rated 'very good' by 27, 'poor' by 5

Events (amongst those who had attended them), rated 'very good' by 18 'poor' by only 1.

### **Quotes**

#### **Positive comments**

'Came to London to NSUN offices and had a really good chat about what was going on. Very welcoming and informative.'

'They are always a friendly and helpful bunch.'

'People working / volunteering at NSUN seem genuinely interested in the survivor cause and are not influence by other objectives, such as the necessity to please a local authority or the NHS. Keep up the good work and attitude.'

'I love the newsletter as it's straightforward and easy to navigate...I really appreciate clear explicit contact instructions, who to contact, when and how.'

#### **Negative comments/suggestions**

##### **NSUN approach**

'The events have seemed to be about DOH officials unveiling their plans and looking for feedback. I'd like it to be the other way round, where users work out what they want and then tell the DOH.'

'NSUN is a useful means of keeping in contact with what's going on. I feel it could be more radical.'



### **Disability access**

'NSUN AGM and NSUN office not disability accessible.'

### **Problems using website/for those with no access to internet**

'I am not aware of regional groups which I might be able to participate in and no contact names/numbers of whom I should speak too, therefore I do not want to sound negative in my approach in the past two questions. If someone can send hard copy literature to me on the aforementioned it will be very much appreciated.'

'I have tried on several occasions to join formally and have on several occasions reached the point where the website indicates that we will be contacted - we never have been so far, so our formal membership has yet to be completed.'

### **What in your opinion would be the 'ideal' for a service user/survivor network? How will it look, what will it be doing?**

**(77 comments, numbers are for times something was mentioned)**

Again, this question elicited much repetition of points people had already made in previous questions, particularly the one about what NSUN will be doing in 1-3 years. Where it seemed more appropriate, I have added some of the quotes from this section to the results for that question.

Independent funding, critical voice – 6

User – led – 5

Regional reach – 4

Supporting local networks – 4

Personal, not over-professionalised service – 3

Providing face to face networking opportunities – 3

Respectful and understanding – 2

High profile – 1

Doing media work - 1

### **Quotes**

#### **Ethos/working style**

'It will focus on involving its members rather than its employees.'

'Co-ordinating the service user voice (at the moment, too many little, 'cherry-picked', unrepresentative groups providing so-called service user involvement).'

'Avoidance of corporate models and boring language that turns off a number of service users.'

'It would not be frightened of looking critically at the charity sector as well as government and established psychiatric practice.'

### **Partners**

'I would like to see development in contacts with advocacy, especially with UKAN and a4a. There is a crying need for mental health advocates outside the compulsory boundaries.'

### **Accessibility/reach**

'It would cover a wide range of views and experiences. It would particularly seek to involve and represent people on the receiving end of compulsory treatment and working class people of all ethnic origins who I believe are under-represented in user activism.'

'A differentiated portfolio of activities and resources that offer different people different things at different stages of their recovery journey or their later development as advocates or as activists.'

'To engage more with people who don't have a diagnosis in order to foster networks between the two groups (i.e. 'open' events where people who don't necessarily experience mental distress can learn and contribute in their own ways).'

'Offers a comprehensive database of survivors in the UK and also abroad. We need more details for each survivor (portfolio of skills, website, sample publications if they exist, interest in speaking up, etc).'

'I think the terms 'service user' and 'survivor' are too restrictive. In my experience there is an understanding that to be a 'service user/survivor' you have to have been on a psychiatric ward, sectioned, or to have a psychiatric diagnosis. Yet there are many people like me who have been deeply affected by the psychiatric/psychotherapy system and want their voice heard, but don't fit these categories.'

### **Specific suggestions**

'Campaigning against coercive psychiatric and psychotherapeutic treatment.'

'Becoming a source of clear information on what service users find helpful in treatment. Informing service users - and indeed the public - about what to do if you are not satisfied with the treatment you are getting ( how to get a second opinion, how to avoid coercive treatment, where the best-rated psychiatric facilities are, and so on). All in all, empowering strong consumer influence on the part of service users.'

### **What is the single most important issue for you regarding mental health?**

**(77 comments, some people did mention more than one. Numbers are for times something was mentioned)**

Fighting discrimination and stigma – 10

Need for person centred/holistic care – 9

Cuts – 8  
People forced into work/lack of support when in work or to find work – 7  
Prevalence of the medical model – 7  
Hostile government – 6  
Finding support to think positively/have confidence/somewhere to turn – 6  
Poor quality services – 5  
Compulsory treatment – 3  
Access to community mental health services – 3  
Need for better training for health professionals – 3  
Need for real user involvement in all geographical areas – 3  
Need for service user voice to be transmitted to policy makers 2  
Availability of counselling – 2  
Equalities issues – 2  
Need for fairer benefits system – 1  
Housing – 1

## **Quotes**

### **Stigma**

‘Eradicating stigma, primarily in the public but most pertinently in NHS workers.’

‘The demonising of disabled people and characterising us as scroungers, defectives, or simply as a burden on society.’

### **Care and treatment models**

‘The almost complete failure of the medical model’

‘A service or network of support that genuinely puts the person in receipt of support at the heart of what it does.’

### **Cuts**

‘People falling through ever wider holes in the support network as the cuts are biting.’

### **Employment**

‘Supporting the person to overcome their own barriers and achieving some personal level of wellbeing, not forcing them into work or situations where this can become detrimental to their wellbeing. Giving them time to rebuild and establish themselves positively.’

### **User involvement**

‘Genuine user involvement in mental health commissioning – it’s patchy in terms of geographical spread and quality.’

## **What single thing could the present government do to help mental health service users and survivors?**

### **(77 comments)**

It might have been better to say 'government'. Saying 'the present government' led to some people giving the entirely understandable response of 'resign', rather than something more constructive!

Fund more services/no more cuts – 22

Listen to people/involve service users in planning – 10

Speak out/legislate against discrimination/educate the public and employers – 9

Resign – 5

Provide more work opportunities/support when in work – 5

Stop forcing mental health service users into work – 4

Focus on person-centred treatment – 4

Stop drug-centred treatment – 4

Fund statutory mental health advocacy – 4

Reverse NHS reforms/don't privatise services – 3

Improve training for mental health professionals – 2

Scrap the Mental Health Act – 2

Invest in community mental health services – 2

Clarify the personalisation agenda – 1

Abolish co-ercive treatment – 1

Ensure equitable mental health service provision across the country – 1

Fund examination of the underlying causes of mental ill health – 1

Stop labelling people – 1

Simplify benefits – 1

### **Quotes**

#### **Cuts/privatisation/funding**

'Don't make cuts to already struggling services, provide more to services so they can achieve successful outcomes for those with mental health problems.'

'Welfare reform has become punitive: research demonstrates we are already a stigmatised, socially isolated and socially excluded group who are less likely to be meaningful employed and be in poor physical health - don't 're-configure' the few services we have left out existence, and don't privatise them!'

'Give us money and support to have more user led projects, self management, and therapeutic groups.'

'Provide every service user in the community with moderate to severe mental health issues with access to a worker (can include peer support specialists) who are Recovery

based workers weekly, fortnightly or monthly as needed. This needs funding. It is worth every penny in the long run.'

'Invest more money especially in talking therapies mainly for more intensive ones than CBT.'

### **Employment and benefits**

'Stop threatening to withdraw DLA from mental health service users who struggle financially already. This places an added burden of stress, which is the last thing we need.'

'It's no good cutting benefits and forcing people into work when there isn't any.'

'Stop the message that work is the only thing which will help mental health service users and survivors without encouraging and funding the services that manage the underlying problems, for example poverty, abuse in many forms, which many charities carrying this role better than statutory.'

'Facilitate access to employment and training in the same way that they do for the physically disabled and to do this for people of all types and educational backgrounds.'

'Stop telling us that we can all 'recover' and get a job - and that this will make it all right.'

'Being expected to volunteer with little prospect of paid employment is not good for people's self esteem or their stability. Having work keeps me well.'

### **Listening**

'Provide a parity of resources compared to that provided for other health conditions and listen harder to people struggling to cope rather than to professionals and drug companies.'

'Listen to them - in some parts of the country mental health commissioning will not be safe in the hands of CCGs. Also mental health service users' voices will be marginalised in the arrangements for Health Watch. Citizen participation is not the same as user involvement which is supported by an experiential knowledge base.'

### **Other comments**

These have been added to the most relevant earlier question.

### **My analysis**

#### **Impact of existing work**

The survey is an overwhelmingly positive endorsement from members of NSUN's work. What comes through most strongly is that it is very important to members that NSUN

exists – that it fills a real gap for a service user-led network that connects the whole of England, communicates regularly with its members and is beginning to be recognised by decision-makers. Significantly, a third of responses about what NSUN should be doing in 1-3 years (and the highest number of any one response) are that it should carry on as it is.

The area in which NSUN is most developed and appreciated is that of information. The website and e bulletins are praised by many. The information seems to be well-pitched and useful.

Although they are not negative about existing provision, some people want other NSUN functions to be developed further, including training, events and local work on the ground. This would obviously be dependent on dedicated funding being accessed. Many also want NSUN's campaigning and media work to be intensified. For some, this is a matter of achieving a higher profile, which might include more reach into government; for others it is about being more overtly critical of government. This is one of a number of contradictory impulses amongst the membership (these are explored more below).

There is one major area of dissatisfaction, and that is with NSUN's regional reach. Many see it as London-centric. They want it to support and publicise activity outside London more, and they want information that is relevant to their own local area. Suggestions include a regional assembly or forum, regional ambassadors and including something from each region in the newsletter.

### **Tensions and contradictions**

The only area other than regional reach where dissatisfaction (often expressed obliquely) is evident from some, is that of the extent to which NSUN is 'professionalised' and 'top down'. Related to this is how much NSUN should seek to work closely with the government, the medical profession and large, corporate charities and how much it should stand part from these and criticise them robustly when required, perhaps aligning itself more with the disability rights movement. There seem to be three camps: a vocal group demanding NSUN be more 'bottom up', less bureaucratic and more critical, working only with others who are 'genuinely user-led' (a contested concept in itself – how is it measured?), a smaller camp arguing the opposite – that it should work more with government and ensure it is taken seriously, and a probably large and not so vocal group in the middle who are relatively satisfied with the current balance.

One comment sums up this contradiction. It suggests that NSUN should be 'high profile but very much led bottom up, not top down.' Combining these two qualities is a real challenge for something that is, after all, a charitable organisation rather than an organic protest movement. I am not aware of other examples of high profile organisations that are genuinely bottom up, but perhaps this could be researched! Or perhaps this debate could be had overtly with members through an online forum or event, to determine the majority view.

The whole (possibly artificial) division between who members see as a 'professional' and who they see as a 'service user' would also be an interesting subject for further investigation, perhaps for a challenging newsletter article presenting opposing views. One respondent explained the frustrations this causes for them: 'although I am very happy in my job and very grateful for someone to actually employ me, I often feel very isolated being both a mental health service user and a worker in mental health - as I feel it is more difficult to get my own views/experiences heard/taken on board - as my role is to relay other peoples experiences/views of using mental health services. And when I do share my views/experiences other service users quite often say "ah, but it's different for you, you're a professional" which is simply not the case! Not sure how to combat this!'

It does feel that within the NSUN membership there are sub-groups with specific experiences and interests (some which the survey throws up include people in employment, people who don't identify as 'survivors', people who have been subject to co-ercive treatment, people seeking drug-free treatment). As some respondents suggest, it might be a good idea to explore creating online sub-networks for them which they could manage themselves. 'People interested in direct action/critical campaigning' could even be one of these groups.

### **Ideas for future priorities**

The clear messages from the survey in terms of future development are:

- NSUN's information role is useful and must be retained.
- NSUN's campaigning and influencing role is appreciated and should be expanded if possible. The ideas from the survey about what the government should do could usefully be gathered into a 'wish list' and presented to government/other organisations as a campaigning tool.
- In terms of new activity, work outside London and work on improving NSUN's nationwide coverage should be prioritised.