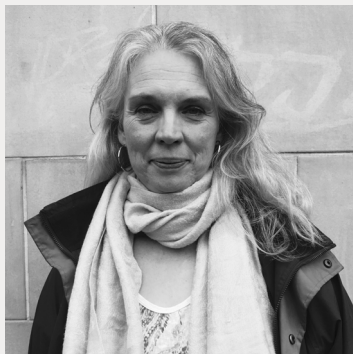


Annual general meeting and members' event

**NSUN members' event &
Annual General Meeting**

**Showroom & Workstation
15 Paternoster Row
Sheffield. S1 2BX**

**Weds 27 September 2017
10.30am – 4.30pm**



Decisions & discussions, soapboxes & feedback

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User Network (NSUN)
2018

Welcome & Thank you



The National Survivor User Network (NSUN) Managing Director **Sarah Yiannoullou** thanked attendees from across the country for coming to Sheffield for NSUN's 6th Annual General Meeting and members' event.

Chair **Stephanie McKinley** set the scene for the day:

"NSUN is now in its 11th year, a testament to our members' commitment to sharing their experiences of mental health with the rest of the community. We are now looking forward to the next decade and, going forward, the Board wants NSUN to be a force to be reckoned with as the go-to-organisation for what's happening on the ground."

NSUN has over 4,500 members, and Stephanie emphasised that in the next decade NSUN would focus on amplifying this potentially powerful member voice to fight injustices and to use its collective power to really make a difference.

"We've taken a long hard look at where you all want NSUN to go. We will continue to act at a strategic level, focusing on working collaboratively, but will not be afraid to walk away if there is no real benefit on the ground."

"We want to be seen as punchier and a lot spikier, reflecting what we are hearing from you, and our Manifesto. We are really looking forward to working with you all as we continue to raise our voices, and use our collective strength for the good of all. That gives you some sense of where we, as a board, want to take this organisation going forward on your behalf in 2018 and beyond."

Apologies were received from the following: trustees - Henderson Goring; co-opted trustees - Joe Kelly and Peter Munn; and from Cluny McPherson (volunteer), Jayasree Kalathil (consultant), Sara Lopez and Nash Momori (Real Insight.) •

"NSUN is now in its 11th year, a testament to our members' commitment to sharing their experiences of mental health with the rest of the community."
Stephanie McKinley

Our business - our people



Soka Kapundu



Mark Wood



Mish Loraine

Item one

Approval of minutes for June 8, 2016 AGM

Stephanie McKinley asked approval of the minutes of the 2016 AGM, as a true record of that meeting. The minutes (within the 2016 AGM report) had previously been emailed to attendees and a copy was included in attendees' information packs on the day.

- Mark Ganderton proposed the motion
- Kirk Teasdale seconded the motion
- Majority approved. No objections. No abstainers.
- Motion carried.

Item two

Trustees' report and accounts

The Annual Report and financial details were emailed to members prior in advance, and included in delegates' packs.

Soka Kapundu, NSUN finance manager, went through headline figures for the financial year 2016/17 as follows:

Income during 2016/17 was £276,427.

Expenditure during 2016/17 was £327,348.

This deficit was financed by using reserves from previous years. Reserves going forward are £47,258, £98,180 in the previous financial year.

Mark Wood, NSUN treasurer said that NSUN had not yet achieved the level of income needed for 2017 to 2018 and it had set up a fundraising committee to look at building a more diverse income stream as grants from funders were coming to an end. He highlighted the online Giving Machine on the NSUN website, and encouraged members to use it when shopping online to increase donations to the charity.

There were no questions from the floor. Stephanie McKinley therefore proposed that the Annual Report and Accounts from April 2016 to March 2017 be adopted.

Approval of annual report and accounts from April 2016 to March 2017

- Fiona Wright proposed the motion
- Mish Loraine seconded the motion
- Majority approved. No objections. No abstainers.
- Motion carried.

Item three

Managing Director's report

Sarah Yiannoullou began her report by saying that many of the challenges for user-led groups and user-led initiatives that NSUN faced when it started 10 years ago are still there:

"We've always found we've had to try a bit harder to get our voices heard and get the support we need, not just in terms of finances, but in terms of recognition and respect."

NSUN launched in 2006 at the 'Doing it for Ourselves' conference in Birmingham, kicking off the idea of an independent, user-led national network. To mark its 10th year, in April 2016, NSUN introduced the fundraising Thrive 10 campaign. To date this has raised £3,000+ from donations. A membership charging scheme has also been introduced to cover the cost of the communication and promotion of events that NSUN does on behalf of allied organisations.

NSUN has been able to carry out a development project looking at its future role. In sessions facilitated by Debbie Roberts and Mark Brown, we reflected on what members had told us they wanted, and what we could do in the future to meet their needs.

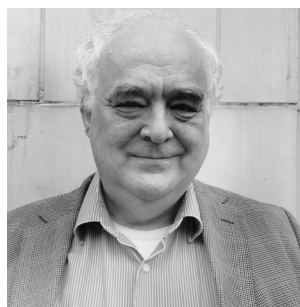
There have been changing priorities shown in the membership survey and Manifesto in recent years about what is most important to our membership. But every year we seem to be facing a situation where we are not sure if we will be able to continue or what we might be able to achieve.



Sarah Carr



Kirk Teasdale



Roger Tuckett

"Thank you to people who have contributed to articles and blogs; more than 90 blogs have been published, as well as articles, thanks to the hard work of Stephanie Taylor King."

Voluntary sector facing changing climate

NSUN is facing the same struggles confronting the voluntary sector as a whole. Figures from The National Council of Voluntary Organisations (NCVO) show that although smaller groups make up 80 per cent of the sector, they receive just 20 per cent of the funding. A review of NSUN's member groups completed at the end of 2016 revealed that a shocking 160 groups had closed in 18 months. 55 groups joined in the same period, so the net loss is high; in previous years there has been a drop of only around 20 - 30 groups.

This snapshot shows the changing shape of the voluntary sector, with smaller user-led groups finding it particularly difficult to survive. This doesn't look like it will get any better any time soon. NSUN's vision is to create a diverse, inclusive and influential network. This isn't about keeping NSUN as an organisation, it is about the survivor movement continuing to have a collective voice and collective influence.

Co-production

Over the last couple of years involvement and co-production have been co-opted in a way that probably frustrates many people. While it is good that statutory services are doing more in this area, the way that they do it is open to question, and sometimes not recognisable as proper co-production. Bigger organisations, from both the private and voluntary sectors, have moved into the co-production space that user-led organisations fought hard to carve out for themselves. Unfortunately this can be completely counterproductive, and work to the detriment of people's experiences of services, rather than its improvement. In an environment of competitive tendering processes and collective commissioning, user-led organisations often cannot compete.

Said Sarah: "But it's not all bad news: the report also gives an overview of our achievements. We've continued to produce bulletins, to help to build links, and we've continued to facilitate consultations and focus groups to

get our voices heard. We've also managed to shoehorn our way in to important consultations when we have not been invited. For example, we organised a quick virtual consultation group to make sure that our members' views were included in the government's Mental Health Research Policy, thanks to Sarah Carr and Emma Ormerod.

"We're still here, and we have achieved a lot, but there's a lot more that we can do. We know our communications could be better, we need to be telling people what we're doing more regularly and more frequently. We've been involved in lots of conversations and policy work but often so busy doing it, that we don't tell you what we've done, and the impact it has had.

"Thank you to people who have contributed to articles and blogs; more than 90 blogs have been published, as well as articles, thanks to the hard work of Stephanie Taylor King."

Future focus

Why does NSUN exist? When we setup, we had a very clear brief, it was about linking individuals, and linking and strengthening service user groups, in order to involve and influence people. Simply put, we exist to make sure that the voice of experience is heard.

Our renewed sense of purpose is about making sure your voice is heard loud and clear, that all our work links directly back to our Manifesto, and to what members have told us. We want to make sure that the things we do have a direct impact on our membership, improving lives and changing things for the better.

We have also focused on the language of services and service users, although we have maintained the survivor identity as well. Service user as a label is a description of the service response to distress rather than the experience. So we started to talk about the discrimination and disadvantage people suffer as a result of their distress. It is about people's identity being self defined and affected by particular things rather than a label given by others.

Our business - our people



Edwin Martin



Tina Coldham



Dominic Makuvachuma-Walker

The projects and the work we are planning have come directly from the discussions and ideas that people had in the development process. Looking more widely, we will be more challenging. Involvement work can start to feel like you're feeding the beast, so we will be involved only at a certain level, and only then if we can really be certain there will be an impact. And although there are some things we will have to stop doing, there are also a lot of new things we will begin to do.

Question from floor, Paul Fraser: Do you get grants for user groups from people like Comic Relief? Do you give user-led groups grants?

Sarah Yiannoullou: We have had grants from some of the main funders like Esmée Fairbairn, Comic Relief, Tudor Trust but we don't give out grants ourselves. When we work with groups or individuals we give payments to those who are able to receive them and we have supported user led groups and initiatives in a variety of ways.

Alison Faulkner and Debbie Roberts will soon be talking about 4Pi, Emma Ormerod will talk about the Survivor Researcher Network (SRN) and Stephanie Taylor King is going to talk about benefits. Mark Brown will talk about the development process. We will also talk about protecting the survivor history movement.

Question from floor Dominic Makuvachuma-Walker (trustee): Can you tell us what work you have been doing with underserved communities eg LGBTQ and BME?

Sarah Yiannoullou: We have been working with Lankelly Chase, and people who were members of Catch-a-Fiya, a user-led BME network that sadly closed a couple of years ago. It is an absolute priority of NSUN, and you will hear more when we see Raza's Griffiths video presentation shortly.

Item four

Election of Trustees

NSUN's articles of association require that we have no less than three, and no more than 12, trustees. Trustees are required to retire after their third year. Following a formal skills audit of the current board, a recruitment process for new trustees is undertaken.

Trustees remaining on the board currently within a three year term are:

- Alisdair Cameron
- Dr Sarah Carr
- Julia Smith
- Dominic Makuvachuma-Walker

Trustees nominated for re-election:

- Eleni Chambers
- Henderson Goring
- Stephanie McKinley (chair)
- Mark Wood (treasurer)

Resigned from the Board:

- Kathleen Lovell
- Paul Valentine

New nominees:

- Daisy Abraham
- Joe Kelly*
- Peter Munn*

*Joe Kelly and Peter Munn wish to act together as a joint trustee.

The motion to reelect Eleni Chambers, Henderson Goring, Stephanie McKinley (chair) and Mark Wood (treasurer) was proposed by Nigel Moyes and seconded by Dorothy Cook. However, following debate from the floor, it was agreed that voting should be for each trustee on an individual basis. It was agreed that although Henderson Goring had not been able to attend the meeting, he should be included in the voting. However, as no information about him had been submitted, some members abstained. Fiona Wright asked if the chair



Daisy Abraham



Sarah Corretto



Nigel Moyes



Alisdair Cameron

could look into the rules on support and submission of information for future reference.

- Eleni Chambers
Proposed: Nigel Moyes
Seconded: Dorothy Cook
Motion carried.
- Henderson Goring
Proposed: Dominic Makuvachuma-Walker
Seconded: Dorothy Cook
Motion carried.
- Stephanie McKinley
Proposed: Mish Loraine
Seconded: Nigel Moyes
Motion carried.
- Mark Wood, treasurer
Proposed: Julia Smith
Seconded: Daisy Abraham
Motion carried.

New Trustees:

- Daisy Abraham
Proposed: Marc Ewen
Seconded: Eleni Chambers
Motion carried.
- Joe Kelly
Proposed: Jo Josh
Seconded: Dorothy Gould
Motion carried.

It was agreed not to vote for Peter Munn as there was no information about him available and he had not made a formal application to be a trustee, but had been nominated by Joe Kelly.

Honorary Officers

The Honorary Officers are elected for a one-year term after which they are eligible for re-election. Nominations for each Honorary Office have been supported by at least two members.

Nominations for Honorary Office are:

Chair: Stephanie McKinley
Proposed: Dorothy Gould
Seconded: Alisdair Cameron
Motion carried.

Future voting system: following concerns expressed by members that some people were not comfortable voting by a show of hands, or voting for someone they had no information about, Sarah Yiannoullou reassured members that these comments would be taken away and considered for the next AGM.

Items five & six

Appointment of Auditors & Remuneration

Stephanie McKinley thanked the auditors (Martin Morrison and Co Ltd) and recommended their re-appointment.

Proposed: Mark Wood
Seconded: Mish Loraine
Motion carried.

The auditor's remuneration for this year was put to the vote.

Proposed: Julia Smith
Seconded: Mish Loraine
Motion carried.

It was agreed that the Executive Officers would be authorised to agree the amount of remuneration for this year with the Auditors.

Items seven & eight

Any Other Business / Special Business

As there was no other business, the AGM closed at 12.45pm. •

Our Manifesto in action

Presentations & Workshops



Members' manifesto for mental health



National Survivor User Network

We aim to:

1. Address the injustice and harm that have been caused by cuts to public funding and changes to the benefits system
2. Make the policy of 'getting the right support, at the right time, in the right place, from the right person' a reality
3. Pressure mental health services to make the principle of 'nothing about us without us' a reality at all levels, through meaningful involvement in decisions about our own individual care and genuine co-production to develop services
4. Work together with people from socially deprived and marginalised communities to determine their support and develop alternatives
5. Challenge institutionalised discrimination and put equality back on the agenda for mainstream mental health services
6. Call for a reform of the Mental Health Act 2007 to make it fully compliant with human rights legislation and ensure that people are not harmed or abused
7. Reflect the social model of disability and promote informed choice and alternatives to medication
8. Reclaim, challenge and revive survivor knowledge and research

Our manifesto in action



"The big breakthrough we made was through looking at the Members' Manifesto – right there was a fantastic programme of work to take forward."

1. Mark Brown, Social Spider

Mark outlined the process he and Debbie Roberts had followed to help NSUN rethink what we do, how we do it and what we're about. In thinking about NSUN going forward, things are getting much worse for people who have a long-term experience of mental health difficulty.

There are a group of people who are not being served very well by policy. They're being bitten by things like benefits reform, and by reduction in funding of local authorities. So we thought maybe one of the important things for NSUN to do was to be very clear about what we're focusing on - people who were getting the sh***y end of the stick.

That's what it's really about – that renewed sense of purpose – which gives NSUN a better opportunity to move into spaces that very importantly aren't being occupied by other mental health charities.

We looked at what the other mental health charities were doing and realised there's a big space for people like us. We're not really being represented very well, we aren't having the impact that we need to have.

That was part of the repositioning and rethinking. The big breakthrough we made was through looking at the Members' Manifesto – right there was a fantastic programme of work to take forward. •



"We want to promote survivor knowledge and research, making it powerful, credible and really legitimate research evidence, which is not just written off as being anecdotal. That's our overarching aim."

2. Dr Emma Ormerod, NSUN researcher

I'm going to talk about how the Manifesto was put together and then I will talk a bit about the Survivor Researcher Network (SRN). The Members' Manifesto is an evolving document which we initially developed in 2015, but we realised that it needed updating.

We draw things together using lots of different sources. One of those is the annual members' survey, another is the top 10 issues, where we ask what's the single most important issue for mental health, and then the responses are fed directly in to the Manifesto. But we also use things like the AGM soapboxes, the events, the other data that we're drawing from all the time.

In terms of Point 8 in the Manifesto, which is "Reclaim, challenge and revive survivor knowledge and research" – this is about drawing on our own lived experiences, our views, our beliefs, our perspectives, to produce our own knowledge and research evidence.

The evidence base in mental health research is still a clinical one – knowledge is produced and understood within the context of the medical model. Numbers are still presented as being the main valid form of data. We want to question that, and challenge that hierarchy of evidence and that medical model that still exists. We want to promote survivor knowledge and research, making it powerful, credible and really legitimate research evidence, which is not just written off as being anecdotal. That's our overarching aim.

We really want to revive the Survivor Researcher Network and bring people together. If you're interested please let me know, whether you are experienced in research or if it may not be something you've done before but you're interested in doing. We've recently put together volunteers across the country to form a new SRN working group and we're working on what we want to do next including finding some funding, so it would be great to see what you'd like to see moving forward. •

Our manifesto in action



“ We want to help develop and support a network of service users, survivors, campaigners and activists and to get our voice heard with service providers, with the regulatory bodies, with politicians, and in research and anti-stigma campaigns.

3. Raza Griffiths, NSUN London coordinator

I previously worked for NSUN helping to develop the 4Pi framework and am based near London. Sometimes when people think of London they imagine people who live there are somewhat privileged compared to many parts of the country. But within spitting distance of Big Ben and parliament, which symbolises political power and the city, the bastion of financial power, there are many of the most deprived boroughs in the whole country. As in many other parts of the country, benefits cuts are driving people to take their own lives.

People are living in unsafe housing as evidenced very recently by Grenfell Tower. There's no coordinated mental health strategy for our young people; communities don't trust the police to protect them, and there are more people who are on benefits, or in work that are badly paid and on zero hours contracts, than are employed. London is also a city of great diversity, not just in terms of extremes of wealth and poverty, but also as the site of the country's biggest BME communities who continue to experience particularly bad outcomes and experiences in terms of mental health services.

All of these factors affect our mental health and my job is to help engage mental health service users and survivors to get their voices heard clearly on all of these issues. Mental health, poverty, discrimination, whether on the grounds of race, sexual orientation or gender - these are all political issues. We refuse to be pigeonholed into some safe mental health agenda. This is about social justice.

We want to help develop and support a network of service users, survivors, campaigners and activists and to get our voice heard with service providers, with the regulatory bodies, with politicians, and in research and anti-stigma campaigns. In short, we want to engage with all the groups and power-bases in society that impact our wellbeing. How we go about this is definitely something we want your input on.

One of the key things we will be promoting is the Kindred Minds BME MH-service-user-led manifesto. This is a unique resource that's been developed by mental health service users, and it encapsulates many of the things I've talked about. It links different areas like early years and education, benefits, policing, housing and so forth around mental health, and promotes the need for a joined-up strategy to tackle socio-economic issues and racism that will improve our mental health.

I'd really like to know more about your mental health and social justice interests, and some of the wonderful work you're involved in. It's only by working together, and linking up much more widely with the broader social justice issues that are affecting our mental health, by being united, that we can bring about the kind of world that we all want to see. •

Our manifesto in action



"In the last 12 months, we've really seen people picking it up and running with it (4pi), which has been incredibly reassuring. It's also inspiring that the framework does work for people."

4. Alison Faulkner, consultant

I've done a lot of work around the 4Pi involvement standards. This is the "feeding the beast" part of NSUN's work I fear, which is a shame, but I try to make it more challenging and spikier. The 4Pi standards are: Principles, Purpose, Presence, Process and Impact.

We've worked with Lincolnshire Partnership Foundation Trust over the last couple of years which has been a very positive working relationship. It shows how difficult it is in some trusts to get involvement or co-production really established and to get any funding in a sustained way. The person we've been working with there has had some money; occasionally she gets a bit more and she brings us in again. But in those sorts of situations we need to see how we can make things happen in a more sustained way, for her and for the future.

We've also worked with Rethink, and a few other organisations, to help introduce the 4Pi framework and integrate it into their involvement and co-production work, developing it in a way that works for them. In the last 12 months, we've really seen people picking it up and running with it, which has been incredibly reassuring. It's also inspiring that the framework does work for people. The time spent going round the country and talking to people about what makes it work has all been worthwhile – the framework really does mean something to people. •



"People I meet say it's bldy fantastic! We don't dictate how organisations should do it, we say this is the framework, and you need to make it your own, and we can help you to do that."**

5. Debbie Roberts, graphic facilitator

People I meet say it's bl**dy fantastic! We don't dictate how organisations should do it, we say this is the framework, and you need to make it your own, and we can help you to do that. We can have those conversations in a creative way.

Over the years in AGMs, people have said we want to be a part of this lovely graphic that you do. We've had graffiti walls, things on tables, and this year you are part of the graphic. I'd like to invite you to use words, cartoons, doodles, drawings, emotions, feelings, whatever you like. If you're shy you can doodle on your tables and then stick them up. •

6. Sarah Yiannoullou, Managing Director

Around the room we've put up Debbie's work from other years and events. Another important piece of work I wanted to highlight is the members' campaigns that we started about a year ago. This is where someone raises their own individual issue with us, where they want to find out more information, and find out the experiences of other members that might be similar. We support them to do that work and to have access to the rest of the network. There are some examples in the annual report. The campaigns can be scaled up to a national level or they can just use it locally. That's another important way we'll be taking the Manifesto points forward. Thank you to everyone who contributed so far. •



Soapbox



1. Roger Tuckett NSUN member

“

I seem to remember about 2000 years ago there was another story like this in the eastern Mediterranean. There was no room in the maternity department then, there was no room at the inn, but I think the parents found a solution. The voluntary sector came to the rescue and they found a stable. I'm pleased to say the baby was born safely and went on to do great things.

”

On the way here, I was reading on the train an article about Boy Y, who desperately needed an in-patient bed, and there were none available. I thought I'd heard this story before about three weeks ago about Girl X. The extreme shortage of beds is scandalous. In my part of the world, two mental health wards in a general hospital are about to be closed, or are threatened to be closed, because the hospital wants to use the space for knee and hip replacements, as they make much more profit out of that. There's no space for the mental health patients elsewhere.

I seem to remember about 2000 years ago there was another story like this in the eastern Mediterranean. There was no room in the maternity department then, there was no room at the inn, but I think the parents found a solution. The voluntary sector came to the rescue and they found a stable. I'm pleased to say the baby was born safely and went on to do great things.

On the 31st May, a guy called Jeremy Hunt told Radio 4 listeners that he was presiding over the greatest expansion of mental health services in Europe. And other times he was saying a billion more pounds was being spent, but does anyone know where it's gone? It's lost and gone missing. I've lost a lot of things in my life - I've got a bipolar diagnosis, I've lost my house, career and my hospitality business and my children - they were alienated from me because I had mental health

problems. I lost a lot of money but not a billion. Can you help look for it? Is it under the table? Where has it gone?

One of the pictures that often comes up is Arlene Foster who got a few extra votes in the election. She got her billion and why haven't we got our billion? I think there are many people who are willing to help and some things I've been doing recently suggest it's possible. Talk to people! Someone called Jeremy Corbyn is saying people should have a say in how society is run. Put power in the hands of people. Can you help us?

Anyone who can use twitter, can you put a photo up of Arlene Foster shaking the PM's hand with her cheque saying we want ours too? I wrote to my local MP (that was), he's just got onto the health committee and has military connections, and said we need a big push on mental health. He said to me I think we're about to 'crest the hill' (a military term) in parliament. He finished by saying thank you for your support. I thought I was supposed to be thanking him for his support but he was thanking me. I think there's lots of people out there who are willing to work with us, but I think the time has come to find that missing billion, and add another two billion to it. We can do it if we work together because the time is right to do it. •



2. Alisdair Cameron NSUN trustee

“

We pulled our recovery college, ReCoCo (Recovery College Collective) out of the local NHS trust and we put it in a building called Broadacre House along with great chunks of the community sector. What developed is something we call an austerity flower (thanks to Mark Brown for that term) – a social project that's bloomed against the odds. We were all thrown together in the building out of necessity, and it has just worked and has come from serendipity, has happened organically in very trying circumstances.

”

We mustn't think of ourselves as special, we are no more special than anyone else because there are many other people out there doing what we do all over the country. That's very important - it's not exclusive, it's not proprietary, or owned by anyone in particular.

We pulled our recovery college, ReCoCo (Recovery College Collective) out of the local NHS trust and we put it in a building called Broadacre House along with great chunks of the community sector. What developed is something we call an austerity flower (thanks to Mark Brown for that term) – a social project that's bloomed against the odds. We were all thrown together in the building out of necessity, and it has just worked and has come from serendipity, has happened organically in very trying circumstances. Newcastle and Gateshead, particularly local authorities, have suffered tremendous cuts.

Mutual benefits are key, it's reciprocal. Not just that, it's open to all comers, all the crossovers: marginalised communities, drug and alcohol services, family services, learning disability, the whole lot. Everything gets shoved into mental health. But we don't have mental health problems in isolation; we have all different aspects of our lives, and we need to recognise that, and not just adhere to one label.

This takes me onto ethos. The key to it all is it's not just user-led peer support and people helping

each other - it's open source, it's not proprietary, we don't own it. Just to push back against mental health being the preserve of one group, I'm questioning the category divides that confine the help that's available: professional vs layperson, clinician vs patient, statutory sector vs voluntary sector, primary care vs social care, teacher vs learner, individual vs collective, survivor vs thriver – the whole lot. These are dualisms that get in the way. The way the NHS traditionally goes about things is the professional colonisation that takes place and the whole field becomes stigmatised.

People resent the system and start being defined by their relationship to services. We instead are dedicated to working across sectors and organisations, across professions and across statuses. We reject those boundaries. The greatest asset a city or town has are its people and we need people to feel accepted, understood and supported. It doesn't matter where you're coming from, it only matters where we're going collectively to, and what's strong, not what is wrong. We need the terms 'the client', 'the customer', 'the service user' to recede into the background, so that people aren't defined by their relationship with services provided by other people, and for us to advance as individuals and citizens, to work on a reciprocal basis - one for all and all for one. •



3. Wendy Micklewright NSUN member

I want to thank NSUN for the great newsletters and I also admire its collaboration with other organisations. I was really happy to hear the speech about ReCoCo because I heard about this a long time ago, and I use it as an example (of collaboration). I can only speak from personal experience but when I saw this, it struck a chord with me and I tend to email people to try and move the development forward, so I think the Manifesto is brilliant. I would say only that I think that peer support, or whatever label you want to give it, should be paid or in kind, and I think that idea of self-reliance is a good one. I want to remind you of this Citizen Participation Ladder:

8	Citizen Control
7	Delegate power
6	Partnership
5	Placation
4	Consultation
3	Informing
2	Therapy
1	Manipulation



4. Alan Hartman Manchester User Network

“Going back to user involvement, it's very important to get together nationally. We need cross-area support. We need to know all the user groups and contacts in this country and help each other now because things are getting worse. In Manchester, the cuts have been enormous, our user group is being ripped to shreds, we have no funding. They don't like it because we speak up. And that's the same around the country.”

I'm the golden oldie of service users - 47 years! Firstly, the history of user involvement is very important, it gives us identification. In the days of the 1970s, we were activists and militants. You wouldn't be here now if it wasn't for those boys. Basically, not only is everything being cut, user groups are being dismantled, no funding.

All the old figures are coming back, discrimination. The Mental Health Act being disregarded. The Human Rights Act being infringed. I ask myself, where are all my friends? The users that I knew when I was in the hospital and before that? Firstly, they can't use computers, they're in poverty, they've had their benefits taken away. Where are they? They're in long-term hospitals, medium secure units because there are no community services. They've been discharged, they get ill and they end up in a private hospital - that's where all your money's going. Secondly, where are they? On the streets of Manchester and I'm sure it's the same all over the country. And something that people seem to be a bit ashamed to say, where they are... in prison. They end up on charges because there aren't any beds. A lot of them get charged and go to prison. They stay in there and then come out of hospital on a section 37/38 and then they're back in the mental health system and the money then is used again.

Going back to user involvement, it's very important to get together nationally. We need cross-area support. We need to know all the



user groups and contacts in this country and help each other now because things are getting worse. In Manchester, the cuts have been enormous, our user group is being ripped to shreds, we have no funding. They don't like it because we speak up. And that's the same around the country. The Charter Alliance is a group that supports service users, I wouldn't be here now if it wasn't for them. So we need to help each other. I have here a checklist of all the things that are required for genuine user involvement - it says you should be funded for expenses, no discrimination, and on. It needs updating, it also has a ladder of involvement. We've also done case studies with the real evidence about what's happening to service users. •

5. Chris Lodge NSUN member

"If you do, as you say in the Manifesto, pressure mental health services, it is our experience they will kick against you, they don't like being pressured. They like being worked with and although it's tokenistic in a lot of people's experience, I think if you can get involved with the following things: to steer, to be expert, to work together, to advise and to use experiences."

The last time I did anything constructive with a box I slept in it, so hopefully I'll do something more constructive today. What's been said here in the presentations has made me think, and I'd like to explain about the work that we do in Lancashire Care. It's called Experts by Experience and the idea behind it was to work with a manager of the LCFT (Lancashire Care NHS Foundation Trust) mental health network to get ourselves involved in all aspects of the delivery of care to the mental health community in Lancashire.

It's been very successful. We've been training people about how to liaise with service users and we've been giving a stamp of approval for certain pieces of work that came through us from the start through to the design and implementation. Predictably there's been a reshuffle in order to save a few levels' worth of salary in the NHS in Lancashire, and the post of the lady who was supporting us has gone. Almost amusingly, in the sense of people trying to get involved as service users in the delivery of service and in services generally, we find and know the degree of tokenism involved.

People were told to redo their paperwork if they wanted to get involved with the new manager related to that service. That group had been operating for three or four years very successfully. It formed itself, it had its own constitution, it presented to LCFT managing directors - and that's what happened to it. Although it didn't have the



6. Daisy Abraham NSUN trustee

success in the long term we wanted, I still believe it's the way to try and get a voice. If you do, as you say in the Manifesto, pressure mental health services, it is our experience they will kick against you, they don't like being pressured. They like being worked with and although it's tokenistic in a lot of people's experience, I think if you can get involved with the following things: to steer, to be expert, to work together, to advise and to use experiences.

Finally looking at how we might be able to charge for our time, as service users - take with you that you have a CV. If you look backwards as you're doing productive work, you have experience and you create a CV. It's not long until that creates momentum both in your own life and the lives of the people you're working with. And then you can talk to Emma Ormerod about statistics, qualitative measures and generate more momentum because somebody somewhere will see people who are no longer the same cost to the service as they have been. It's simply when things work, people don't require the services as much.

Most of us have come through a recovery journey - we can all remember I did this or that - but we recall very little about the time spent with the psychiatrist, CPN or support worker or any other aspect of the service. Therefore you can start to separate the people from the stories you can tell, and the number of people. That way, if you can tell the professionals that they

will save money, it will register with them. So, again, by doing all those things - steering, being expert, working together, advising, using your experiences, getting into the fabric of your local NHS trust. Go and talk to them and ask them - how can we work with you so that you don't get grief from people saying you're just ticking a box that says service user involvement? How can we get involved with the design of services, what's wrong with services, go and do consultancy work? You might have to do it for nothing for a while but in the end if you can tell them this has saved you this much money, and that's because people are getting better, they can get better quicker and in the way they want to. I think it's worth it. •

I studied law, and if I was to say to you habeas corpus, would you know what that means? It means 'the physical integrity of the body' - it's a cornerstone of British law.

Unfortunately so far we know indirectly, that theory and practice don't add up. So I want to apply the concept of habeas corpus to freedom of choice to not take medication. And I would add to that human beings differ from animals because we think we're great, because we're higher, and we have free will. I want to know why freedom of choice and autonomy adds up to having no choice about what goes into your body. This is just a moot point for now, as this won't happen for years, but I think that it is wrong to force medication on people with no freedom of choice, no free will. If you refuse it, they kick you down and inject you in the a**. I don't think that these doctors have an ounce of empathy with their clients. They're power hungry, they have too much money, no empathy - and that is the technical definition of a sociopath or a psychopath. We're talking about the law, and I'm hurt, because I'd quite like to come off my tablets and I don't have the right to...yet.

Comment from the floor: With reference to Joanna Moncrieff's work with South West London & St George's Trust about the right to come off medication and the Council of Evidence-Based Psychiatry. •



7. Mustak Mirza NSUN member

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Last year, I did a lot of volunteering and got involved in lots of things. We need to stand up for justice and humanity – and for that we need love and courage.

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I'm not going to talk about inequality, injustice – we see how it is today. I'm going to talk about my own self suffering and my own transformation.

I'm 62 years old, I have six children and seven grandchildren, which is the best thing that ever happened to me because I love them unconditionally (not necessarily my children...) I didn't have any happiness in my own childhood, only from my grandmother. I never really had any love from my mother or father, he was never there. When I came to this country, I went to secondary school. I came over with 5,000 other immigrants, I got bullied.

But then in my youth, I always worked. I knew I had a problem, I felt sad, I would cry inside, but I always went to work. I got married in '77 in India, my father got me a bride. She was generous and compassionate - I didn't have any experience with the opposite sex. Then we had our first child which was one of the happiest times of my life. But that was my only happiness. In 1980, I was driving a black taxi in Birmingham and I had all this pressure and anxiety, but I didn't know what to do. It got so much and the only way I could deal with it was to hit the bottle. I was born a Muslim, conservative family – drinking not allowed.

Then I had a complete breakdown and my life fell apart. But my wife stood by me, I was in hospital for a year. In the last six or seven years I lost my wife. I've become a sole survivor. I was a self-centered

person. I formed this empathy in myself. Now when I love something it gives me power. I look at my life and it's like two halves. My wife had all this compassion I never had. Now it's my turn; she's gone and I am giving something back to my society to be kind to myself, family and community. I'm not a religious person but I have friends in all communities – LGBT, Afro-Caribbean, Jewish, Indian, Muslim, every walk of life. Last year, I did a lot of volunteering and got involved in lots of things. We need to stand up for justice and humanity – and for that we need love and courage. •



8. Stephanie McKinley NSUN chair

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We can't do it without you and I want you all to understand that the board is not NSUN – you guys are NSUN... and going forward we will ask more of you in terms of your experiences and how that can influence at strategic levels.

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You see me as your chair, and my profile's in the pack, but I really wanted to talk about where I come from. I want you to know you've elected someone who is going to lead the board thinking about how we get our voices out there more vocally and how we support people to do that. And I wanted to thank everyone here today and all members who weren't here. I wanted to articulate that we've had over 30 articles published, the Members' Manifesto that you guys created, four member campaigns, the launch of NSUN's film, over 90 blogs, the work with the British Institute of Human Rights. I think it's about how we get our voices heard and we enhance those ways.

We can't do it without you and I want you all to understand that the board is not NSUN – you guys are NSUN. And we can't do any of this work without you and going forward we will ask more of you in terms of your experiences and how that can influence at strategic levels. You've heard today about all the work that's been done by individuals which is fantastic. It's then how we take that and make NSUN a charity that people have heard of.

We're a national charity and we're small but we have really big ambitions. I want you to help us realise that I'm committed and passionate about that. We're so unique! And where's our voices with the government? Why aren't we being quoted back in the newspaper? That's where I want us to be positioned. What I'm trying to

say is we will likely be sending out more surveys to know much more about what's happening with you on the ground.

We want to be a more disruptive organisation. But sometimes I want us to say more about the positive things that are happening out there. We don't want to be the ones they just come to for negatives because they'll just ignore us. That's what I want us to do and I'm passionate about that – setting up structures to do that effectively.

I want to say thank you to everybody. We will position ourselves to become spikier. I said that this morning and I wanted to say that again. Then coming from you guys, how do we do that more effectively? It's not a great environment we're in – we are here, still – but it won't be easy to remain like that unless you guys are onboard. You are NSUN – that is the main message I want you to take away. We want you to help us shape our vision going forward. Thanks for your time and I hope you feel you've elected somebody who really wants to do what you want us to do. •



9. Fiona Wright Independent mental health care consultant

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I don't want you guys to go anywhere because I feel like I'm part of something, being included in NSUN. While I totally agree with the previous speaker that we need to focus on the positive, I also want to make people aware that when you're going through those bad situations, it's OK not to be OK.

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I will start off by reminding everyone of a few of the things said from last year - they're in the AGM report if you want to refer to them. Julia Smith said: "It's time to see it's grown from 'Doing it for Ourselves' at the 2006 inception." Kath Lovell said: "How do we look after our leaders?" Stephanie McKinley said: "It's now about sustainability, very much working with local communities about what we do to enable people to carry on the work..." And then what I said myself last year: "NSUN has been described as being about lighting a fire under the issues and then throwing in an accelerant."

People like me – volunteers, activists and individuals - are trying to keep the fire going with our voices and passions. During the last two speakers, I felt very drained and had a bit of an idea that I would put some makeup on to make myself feel a bit better. Then I started to realise that how I felt about myself was very much connected with how I was able to support and do the mental health activism work I'm so passionate about. And combining with what everyone's said today, I feel it's really important to share that recently I protected my twitter accounts and closed the settings on the Facebook pages.

These were places I previously spoke openly about my own mental health and if anybody couldn't be open about their mental health, then they would tell me something and I would try to speak up for them. I haven't been able to do this because of stalking and harassment recently.

But it's about what Stephanie said, enabling people to carry on the work after we're gone. I don't want you guys to go anywhere because I feel like I'm part of something, being included in NSUN. While I totally agree with the previous speaker that we need to focus on the positive, I also want to make people aware that when you're going through those bad situations, it's OK not to be OK.

World Mental Health Day is coming up and it's an important time to focus on self-care. But I haven't been looking after myself, I haven't been putting up boundaries to protect myself and I need to do that. As a person who is known to be quite vocal and extrovert, there are times I feel fragile, and sometimes you will feel fragile. Sometimes I feel strong and there are times when I passionately want to fight for other people. But we can't do that unless we look after ourselves. As per the aviation analogy, put your own oxygen mask on first before helping others. So, I just wanted to say self-care is really important and I hope you all have a fantastic World Mental Health Day. •



10. Nigel Moyes NSUN volunteer

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I look around this room and see NSUN's story on the graphics, and I'm so proud to be a part of this, I want to be a part of this, and to continue to be a part of this. I used mental health services on and off for 20 years until three years ago when I was discharged from secondary mental health services. I'm still very active in the field of service user and carer involvement because I have a voice now I didn't have 10 years ago.

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I look around this room and see NSUN's story on the graphics, and I'm so proud to be a part of this, I want to be a part of this, and to continue to be a part of this. I used mental health services on and off for 20 years until three years ago when I was discharged from secondary mental health services. I'm still very active in the field of service user and carer involvement because I have a voice now I didn't have 10 years ago.

One of the reasons I didn't have it was that 20 years ago I went through domestic abuse, although it doesn't happen to men, so I'm told. But it does. It took me 20 years to talk about it but in March this year, in Ipswich, I did in front of maybe 500 people. They were mainly students who were doing a three-year mental health degree as part of their interprofessional learning.

We need to get that voice, we also have to give people the skills they need to get that voice. There are no children or young people in this audience and that is a challenge for NSUN. People need to be seen, heard and believed, and we need mechanisms to get their voices. If I had had an intervention at school when I was bullied it would have made a lot of difference.

Mental health should be seen as a strength and not a weakness to talk about. Too many people are dying. There should be more support for people to talk about these things and not be stigmatised

or discriminated against. One of the best and biggest initiatives I've been involved with in my own local trust, is that we have one of the most proactive recovery colleges in the county. To close, if you look on that sign there, it says: 'Together we are stronger'. And for me, it's everybody's business that we get involved with this work because it's power to the people and it's the future generations that we need to work with. •

Independent review of the Mental Health Act by Dorothy Gould

Mental Health Act Review

Government plans

To start with these, I'm sure everyone knows that the Mental Health Act is due to be reviewed. Government plans are still under discussion, but there does seem to be a focus on increasing mental health staff, decreasing detentions and further action about over-representation of people from BME communities amongst detained patients. There are some definite strengths to the plans, therefore, and in that sense NSUN does welcome the fact that there will be changes.

However, we also have strong concerns. One is because of the apparent continuing focus on a dominant medical model. If you listen to what is being said, the emphasis is on increasing NHS resources, not on resources also needed for alternative and culturally appropriate models. In addition, although it will be positive if there is more preventative work and less use of detentions, in human rights terms what NSUN would like to see is an end to the use of compulsion.

Relevant parts of NSUN's Manifesto

If you look at government plans for the reform of the Mental Health Act in terms of NSUN's Manifesto, there are some very important points to keep making. It's important that our voices are heard about the models and approaches to use in the reform of the Act, in line with points 2 and 3 of NSUN's Manifesto: 'the right support, at the right time, in the right place, from the right person' and 'nothing about us without us'. Approaches taken to reform of the Act need to be appropriate for all community

groups, including people from socially deprived and marginalised communities, for example people who face additional discrimination because they belong to a BME community, identify as LGB, or T, are younger or older (points 4 and 5 of the Manifesto). Also, one main reason for mental distress is very difficult life circumstances. For these reasons, we see it as vital for plans to draw on alternative and culturally appropriate models as well, with adequate funding for these.

A further important issue is that, while the Mental Health Act still enshrines detentions and compulsory treatment, it is not compliant with the human rights stance for which NSUN stands (points 6 and 7 of the Manifesto); later on in the presentation, I'll also say more about human rights' positions that are being taken up at the United Nations (UN). The Act needs, too, to draw on survivor knowledge and research (point 8 of the Manifesto); unless our experiences are used for reform of the Act, together with research which we've undertaken, reforms made will not be what we want to see in place.

Mental Health Act survey report

A particular issue at the moment is the Mental Health Act survey report from the Mental Health Alliance. Some of you will know that the Alliance is made up of over 60 mental health organisations. The Alliance commissioned a large survey about the use of the Mental Health Act, carried out by Rethink, which invited the views of professionals, people with lived experience, family members and unpaid carers. The report came out



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Dorothy Gould

Mental Health Act Review

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I raised concerns on NSUN's behalf and tried very hard to get problems with the report resolved. The Alliance did acknowledge that the report had inadequate representation from BME communities and that this is an area for further work, but was unwilling to withhold the report until such problems had been put right.

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in July under the title of *A Mental Health Act fit for tomorrow*.

NSUN's position on the report

We think that the report has certain strengths, for example it emphasises the need to focus on human rights. However, there are a number of points about it which are concerning. One is that, although people from BME communities are over-represented in the compulsion system, only 8% of a very large number of people who took part in the survey came from BME communities. Because I was actively involved in Alliance meetings, I asked how many of the 8% had lived experience of compulsory treatment. The answer was that the number was not statistically significant, in other words virtually none had.

Similarly, the report seems unbalanced in that 70% of respondents were women and only 30% were men. The survey on which the report is based was a huge one, of over 2,000 people, and so there needed to be better proportions. Also, the report did not draw out the views of older or younger respondents.

In addition, the conclusions drawn from the findings do not seem to be very sound. One conclusion is that most respondents thought that 'it is sometimes necessary to treat someone in hospital against their wishes and restrict their human rights'. However, questions used in the survey start from the Mental Health Act as it is rather than exploring alternatives as well. The questions also assume that respondents are aware of alternatives and so are in a position to disagree with detention

being used at times of crisis. The report fails, too, to take account of recent human rights' statements which have been emerging at the UN. For a further critique of the report, see NSUN's website.

I raised concerns on NSUN's behalf and tried very hard to get problems with the report resolved. The Alliance did acknowledge that the report had inadequate representation from BME communities and that this is an area for further work, but was unwilling to withhold the report until such problems had been put right. Other points raised by NSUN were also inadequately addressed.

Who signed up to the report?

What is particularly worrying – and this is when the collective voice comes in – is that major mental health groups (e.g. Rethink, Mind and the Royal College of Psychiatrists) are lobbying strongly for this report to be used by the government as the foundation for the reform of the Mental Health Act, despite the report's weaknesses. Another point of concern is that, at the back of the report, there is a long list of organisations which have all supposedly signed up to it. However, as Sarah has pointed out, some of the organisations named there do not exist now and so they could hardly have endorsed the report.

Helpful material from the UN

As I've mentioned earlier, some very helpful material about human rights has been coming out from the UN, for example a report in 2015 from the Special Rapporteur for the UN's Human Rights Council. He has challenged both psychiatric

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Sarah Yiannoullou and I had a meeting with Richard Kelly from the Department of Health. He listened and said he realised that there was a flaw with the report in that it asked people whether compulsion can be necessary, but then did not allow for the fact that people may not know there is any possibility other than compulsion. If you're desperate, you might prefer compulsion to receiving absolutely nothing. There was no scope in the survey to say what alternative measures should be in place.

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practice and the use of compulsion, which again feeds very much into an NSUN agenda. There is guidance for Article 14 of the Convention on the Rights of Persons with Disabilities, and that states that detention and compulsory treatment represent a breach of Article 14. Then there is the 2017 annual report from the UN High Commissioner for Human Rights which contains similar statements. Therefore, it does seem that the UN is beginning to move further on human rights issues. Rather worryingly, the European Committee on the Prevention of Torture is still advocating improvements to the Mental Health Act, not more fundamental changes, but hopefully the Committee may start moving forwards from that stance in the future.

The UN Committee for the Convention on the Rights of Persons with Disabilities (UNCRPD) produced a List of Issues earlier this year for its examination of the UK government about the latter's human rights' record. In that List of Issues, there is a strong emphasis on the need for the UK government to draw on evolving concepts of disability, i.e. not just to stick to a medical model, and to bring detentions and compulsory treatment to an end. The List also contains other challenges to the government, including challenges to its austerity measures. This represents some encouraging UN material, therefore.

NSUN's part in the UNCRPD's examination

What happens when a UNCRPD examination is occurring is that any non-statutory group can send issues to the Committee which it thinks the government needs to

address. NSUN took advantage of that opportunity. NSUN's report called on the UK government to take action in line with the sort of material contained in the Committee's List of Issues. The Equality and Human Rights Commission and related Commissions in the rest of the UK also submit a UK-wide report which again raises issues for the UK government to address. I have somewhat mixed feelings about the final report from these Commissions. The report had a number of strengths, for example a strong emphasis on austerity and the need to address problems that arise from it, but had weaknesses in the sense of keeping to a medical model for mental health service users, not coming out sufficiently strongly about the need to end detentions and compulsory treatment and falling short on some equality issues. I had been invited to contribute to the section on detentions and compulsory treatment and had expected that the much stronger statement in the draft was going to be used, but this was weakened in the final version.

You probably already know what the government's response to the UNCRPD was. As well as failing to deal adequately with questions about austerity and inequality, the government passed over the fact that detentions and compulsory treatment are a breach of the Convention. That has not been very promising.

Action planned by NSUN

A series of actions is now being planned at NSUN. There is a model letter which can be sent to your MP; this summarises the

Mental Health Act Review

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It's a personal choice, but there has been a lot of talk today about taking power from the ground. If you feel strongly about what's happened so far, this is a real opportunity for collective action.

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concerns at NSUN which I've been outlining. A similar letter will go to the leaders of all the main political parties; Jeremy Corbyn has it already, but NSUN will be writing to the others as well.

Sarah Yiannoullou and I had a meeting with Richard Kelly from the Department of Health. He listened and said he realised that there was a flaw with the report in that it asked people whether compulsion can be necessary, but then did not allow for the fact that people may not know there is any possibility other than compulsion. If you're desperate, you might prefer compulsion to receiving absolutely nothing. There was no scope in the survey to say what alternative measures should be in place.

We hope to make contact with all the organisations which backed the Mental Health Alliance's report to explain NSUN's position about it and to see whether they really did endorse the report, or did not really take in the report's content. Then we'll be trying to link with individuals and organisations who would like to join NSUN in making representations to the government about the current plans to reform the Mental Health Act and looking to having our voice represented strongly in the media.

Taking action yourself

It's a personal choice, but there has been a lot of talk today about taking power from the ground. If you feel strongly about what's happened so far, this is a real opportunity for collective action.

These are some of the things you could do:

- Send the model letter which I have been mentioning to your MP and/or go and see your MP with the letter; we have brought a hard copy of the model letter and some information about what to do with it. There will also be a digital copy on NSUN's website
- Enlist support for NSUN's position from other organisations
- Enlist support from individuals you know
- Pass on details of useful contacts to Sarah.

You may also have other ideas about other action that you can take.

Comment from the floor: I see a potential problem. In the 1990s I was one of the representatives that went to Isley Triesse, and they stopped sectioning people which we thought was fantastic. A nurse came and said to me, "I don't know why you think it's fantastic because they're going to prison." That is a very dangerous thing. If you're high and there's no beds, they charge you with a criminal offence. The problem at the moment is our rights are being infringed, the '83 Act is being infringed, the Code of Practice is being infringed. So you need to concentrate on that. Imprisoning people who are high is criminalising mental health users.

Dorothy Gould: Absolutely, this is why NSUN is trying to focus on alternatives.

Paul Reed, Manchester User network: Thank you very much for the work you're doing. Has the media been consulted and have you had any interest from them in what you're doing?

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In theory, there's meant to be a lot of preventative work before people are sectioned, it's meant to be a last resort. In practice I think we all know it's a bit different.

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Dorothy Gould: That's a really good point and it's very much in the pipeline. I totally agree with you that it needs to go to the media. There is also going to be a special edition of the newsletter about the Mental Health Act reform.

Comment from the floor: I'm old enough to have been involved in the discussions around changing the 1983 Act which didn't come in until 2007. At that time, the radical idea was to actually abolish the 1983 Act and start again. That didn't happen, and I have a feeling that this review will be exactly the same: the 1983 Act will stay in place, the 2007 amendments will stay in place, there'll be a new Code of Practice and there'll be a few more amendments. I would like to see the Mental Health Act as it stands abolished because it adds to stigma and it also means that people don't ask for help until it's way too late, because they're worried about being sectioned, and the stigma, and about losing their job and the rest of it.

I also feel that one of the difficulties with the current Mental Health Act is it's just to do with the brain, the mind and diagnoses. If you have a cancer diagnosis and you refuse treatment for your cancer,

that's fine. And I think that it's a discriminatory piece of legislation and any review should firstly look at abolishing the Act. I don't agree with the prison argument either – even if people have committed a crime and warrant going to prison, mental health services there don't work at all. I could go on!

Dorothy Gould: Thank you. That's why, in part of the letter I mentioned, we're asking for a rights-based Mental Health Act which obviously is quite different from before. And I'm sure people will have different views about what problems need addressing, and particularly if the compulsion element of it were to go, so hopefully we can take everyone's views into account when looking at NSUN's way forward.

Comment from the floor: I've never been an inpatient myself, or come near to being sectioned, but I know people that have. One of the impressions I get is that sections are a quick and easy route to get someone into hospital without spending time with them persuading them that going in voluntarily is a good thing to do. A lot could be improved. I don't know the details of the Mental Health Act but certainly there are many practical things that could significantly improve the experience and level of care of people being sectioned. My first question is for that to be considered. My second question is a slightly technical one. Nobody wants to be sectioned. When you're discharged, you get automatically tied into continuing healthcare without going through an assessment system and that may be relevant if you're looking for something like supported housing. So is there an agenda here on the

government to somehow reduce the possible exposure to continuing healthcare costs by avoiding possibilities of automatic entitlement by having people sectioned?

Dorothy Gould: In theory, there's meant to be a lot of preventative work before people are sectioned, it's meant to be a last resort. In practice I think we all know it's a bit different. Yes, the government may well have an agenda for decreasing detentions so that they have to provide less aftercare. Often what the government does is finance-related. From our point of view, we're not looking at people getting fewer resources, we're looking at people getting adequate and alternative resources. Mental health services are often plain just not working, and can be dire, which leaves people feeling worse and not better.

Comment from the floor: It's a public point of interest. I discovered yesterday through a SlaM debate meeting that there will be a debate (free event) on the Mental Health Act on the 22nd November at 6pm. A panel of professorial psychiatrists will debate the point that fundamental reform of the Mental Health Act is required to reduce discrimination and unnecessary detentions. I hope that quite a few service users and survivors will be there, so if you live in or near London I would encourage you to attend and make important contributions based on what Dorothy has done for NSUN. •

Feedback from discussion

Feedback from discussion

Sarah Yiannoullou: We're now going to give everyone an opportunity to discuss and reflect on what you've heard today and also the Members' Manifesto, a copy of which is in your pack. Do the points made make sense to you? And secondly, what do you think the priorities are for NSUN on the Manifesto, and lastly any reflections on what you yourselves will be concentrating on.

Table 1 feedback: The manifesto points do make sense. As far as the priorities for NSUN, we felt that Point 1: "Addressing the injustice and harms that have been caused by cuts to public funding" is nationwide, and so definitely a big priority for us. Point 3: "Pressurising mental health services to make the principle of 'nothing about us without us' a reality" in physical health as well as mental health, and Point 7: "Reflect the social model of disability and promote informed choice and alternatives to medication." And prioritising in our own areas is important as well as the support from NSUN in terms of how we can support each other.

Table 2 feedback: It makes good sense and the summary fits on one page, which is good. We want to connect with Mental Health Europe where there are some good policies and resources, and the connection with UNCRPD is really important. One person's priorities were 1, 3, 5 and 6 (please refer to Manifesto for wording.) There were some questions about definitions eg what are socially deprived and marginalised communities?

Table 3 feedback: We thought there should be more in there about young people. Generally we

were pleased with the Manifesto, although maybe Point 1 could be broken down, and we need a strong voice across all levels, and someone mentioned it's often difficult because people don't know their rights.

Table 4 feedback: We discussed the manifesto and agreed with most of it. The West Midlands Combined Authority's Mental Health Commission has funding for individual placement support (IPS) to help people back to work and give them support when they're in work. I don't know whether this pilot scheme may then be rolled out across England.

Table 5 feedback: We had a very lively discussion and we welcomed the Manifesto. Point 1: "Addressing the injustice and harm that have been caused by cuts to public funding," is valid but too vague, so people would like some examples there. And we also were very interested in Point 7: "Reflect the social model of disability and promote informed choice and alternatives to medication." Some felt it would be good to be developed on more, and others wondered if it is appropriate – and so we need examples for that too, to say why it is appropriate. And the other thing people said about the Manifesto was to put it into plain English. Not sure if that's echoed by others, but several people felt that. Priorities for NSUN we thought should be Point 7 (re social model of disability) and also Point 1, because that applies to so much. About what we can do locally, we're a table from Manchester, we've had a great day in Sheffield and we feel very inspired, but at home the main issue is stepping down. I'm sure we will be using the NSUN manifesto as well as our local charter.

Sarah Yiannoullou: At last year's AGM, the debate in the afternoon was about the social model, so we will continue that debate. And to say about the stepping down issue, we are looking to make that a priority national campaign as well.

Table 6 feedback: We had a general concern about the Manifesto in that some of us felt that the net was being cast too wide, and that NSUN might be setting itself up to fail in some ways, by having such a wide agenda. We had a conversation about the differences between devolution in Manchester, and what it's like in the rest of the country. This is an interesting one to pursue, where health and social care are very much a part of the delivering of mental health services in some areas, but most definitely not in other places. Point 3, "Pressure mental health services to make the principle of 'nothing about us without us' a reality", got the most ticks from all of us because we all want to see genuine co-production and I think that's bringing many of us together here today. An overall summary about the priorities is to do more to bring together other groups working in silence around the country.

Table 7 feedback: One of the reasons for these questions is that we recognise that the points in the Manifesto are broad, which reflect the diversity of views and experience across the network. The next stage is to try to hone what we do against the Manifesto points so we can break them down and, as you say, not cast our net too widely.

Table 8 feedback: We prioritised Point 3, "Pressure mental health services to make the principle of 'nothing about us without us' a

Feedback from discussion

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We all agreed that Point 2, “Make the policy of ‘getting the right support, at the right time, in the right place, from the right person’ a reality” should be a main priority for NSUN. Then we took it a bit further and said we should also challenge institutionalised discrimination, and promote equality, because we’re all individuals with different needs. Services should work around us, not force us to fit into boxes, and make more effective and better use of resources.

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reality.” I mentioned the need for urgency about addressing change to the benefits system, which has resulted in people killing themselves. There was also a general consensus about the principle of real co-production being critical, and a discussion about Point 7, about the social model of disability, whether it needs to be nuanced or transplanted wholesale into the context in which NSUN works.

Table 9 feedback: We want the collective voice of individuals working together. Give the government a much-needed wake-up call to face reality. Lobbying for basic human rights enforcement. Where is the money? What about these new respite centres? Are they going to be everywhere or is it just going to be a postcode lottery?

Table 10 feedback: We all agreed that Point 2, “Make the policy of ‘getting the right support, at the right time, in the right place, from the right person’ a reality” should be a main priority for NSUN. Then we took it a bit further and said we should also challenge institutionalised discrimination, and promote equality, because we’re all individuals with different needs. Services should work around us, not force us to fit into boxes, and make more effective and better use of resources.

Dominic Makuvachuma (trustee): Linking up with people is a really important part of what we’re doing. Today I met a black brother, Chris and we had so much in common. There is just something basic for me that says there needs to be a space for people to link up and connect.

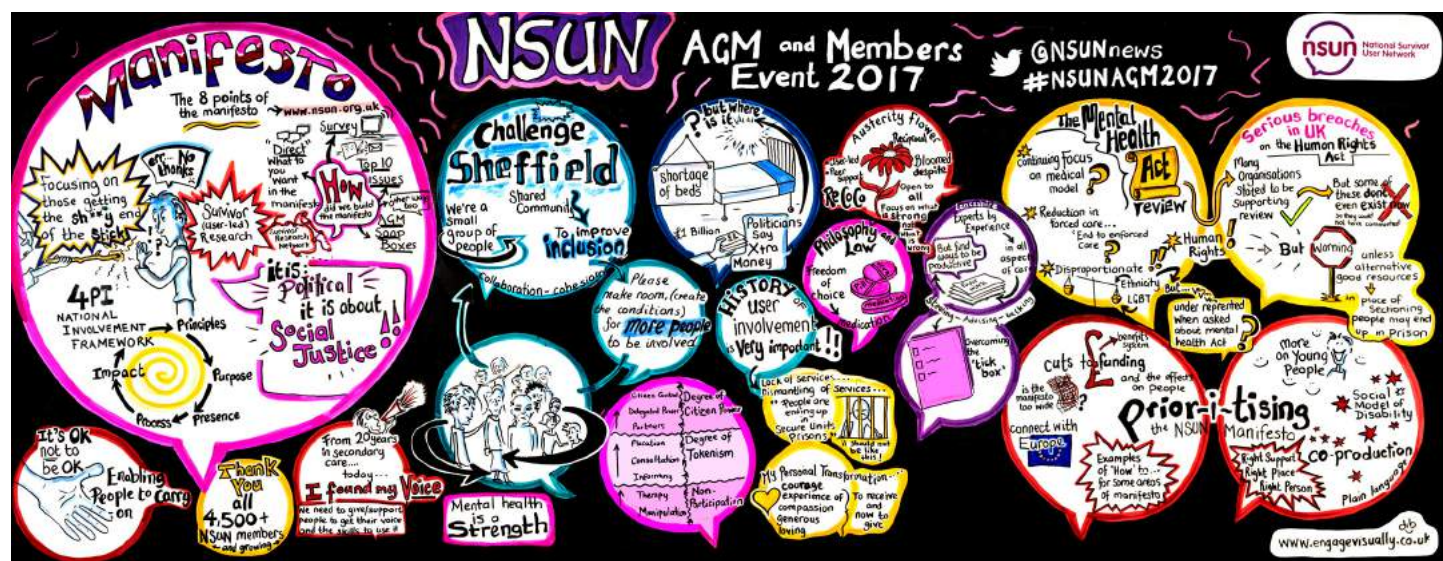
Sarah Yiannoullou: Thank you Dominic. That is an important part of today. Any other comments? That

takes us to the end of business but it’s really important for us to get some reflection back, because there’s been a lot of work on that Manifesto, and sometimes with all the thoughts and views around it, things can lose their meaning. We need to check back and get feedback and then we need to start breaking down those points, and saying this is what we’re going to do and why. We can’t do everything and we’re going to need help as well – linking with others and working with the wider membership, and linking with other networks across Europe. We’re part of the international Interrelate survivor network as well. So it’s about making sure we’re connecting and working with them more regularly.

I just want to say in closing thank you to everybody for coming here today. Thank you to Debbie our graphic facilitator. Thank you to everyone who has contributed. So much from today is important and obviously we will sort out our business and we will do a lot of work to make sure we take your feedback into account so that our next AGM runs smoothly and transparently so that people feel safe and informed. A reminder that today was an important launch day for Challenge Sheffield. If anyone has any more ideas about projects based on what we have talked about today, then please let us know. Lastly, a reminder that there are things you can do to help. It’s your network, it’s not about just helping us, things like going on Total Giving and linking up to the Giving Machine when you shop online. And also providing us with blogs and articles and ideas, and telling us what’s happening locally – We want to continue to promote and protect the independent, direct and collective voice of our network. •



Our Members Event September 2017



This graphic is created throughout the day and helpfully illustrates the key activity, points, thoughts and comments made by attendees. It's a fantastic visual record of the day, especially helpful to those who prefer pictures to words!



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