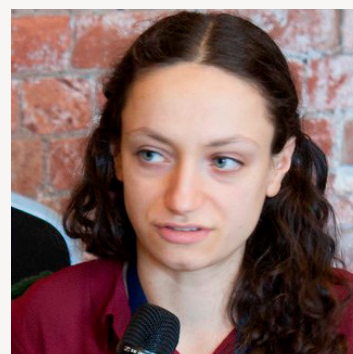
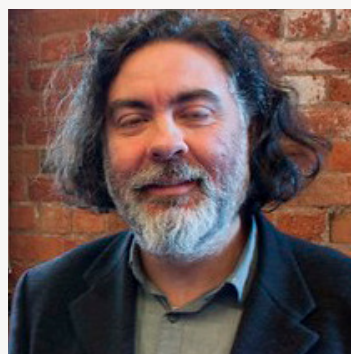
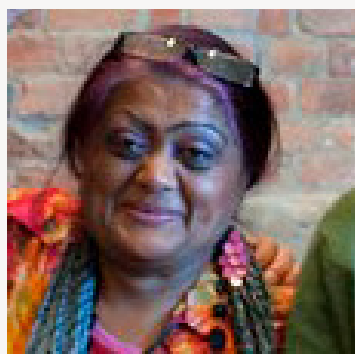
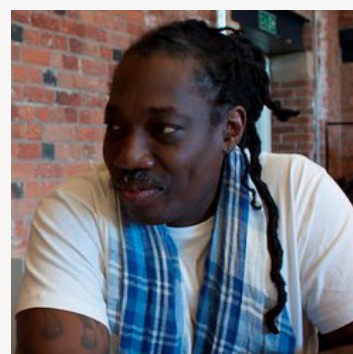
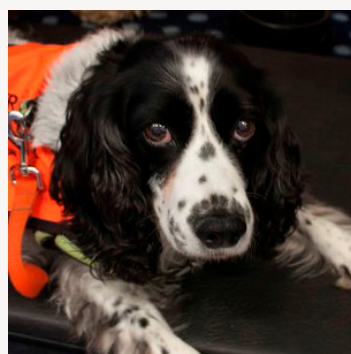
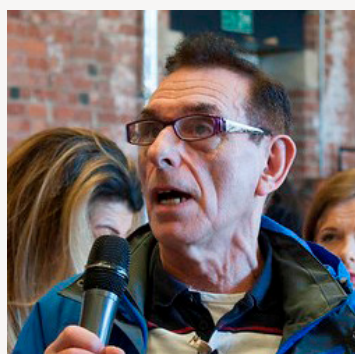
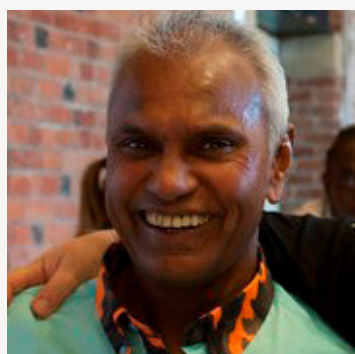
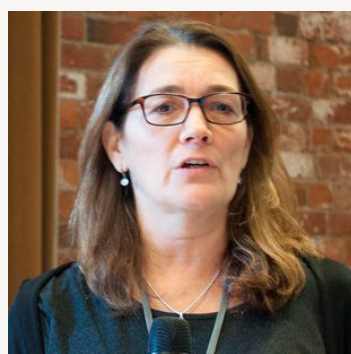
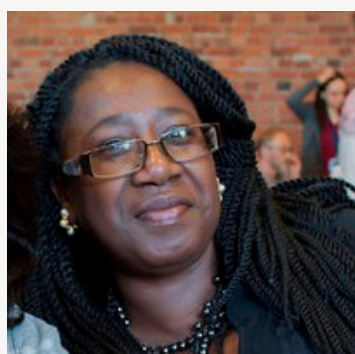
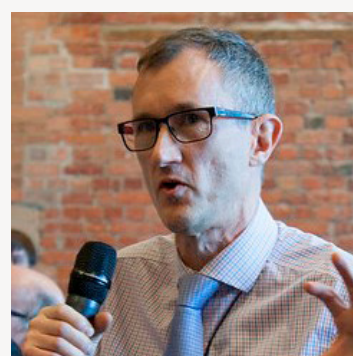
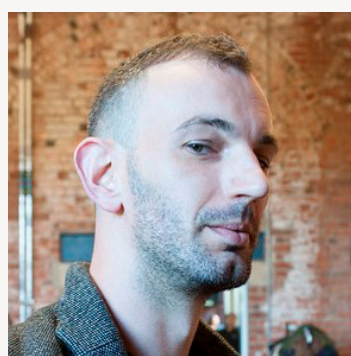


Annual general meeting and members' event – 2018

**NSUN Members' Event &
Annual General Meeting**

**The Roundhouse,
Pride Park,
Derby DE24 8JE**

**Thursday
25th October 2018
12pm – 4.30pm**



**National Survivor
User Network**
PO BOX 74752,
London England
E11 9GD
020 7820 8982
info@nsun.org.uk
www.nsun.org.uk
Registered Charity No.
113598
Company number:
07166851
© National Survivor
User Network (NSUN)
2019





Sarah Yiannoullou

NSUN Managing Director, Sarah Yiannoullou, welcomed everyone to the 7th Annual General Meeting and Members' Event in Derby. The theme of the event - 'The Future of Peer Support' - was about reflecting on what peer support has meant to NSUN members over the last 10 years, how they come together, support each other and find collective strength to change things for the better.

NSUN has promoted the collective, independent and direct voice; but it's not about having one voice. The uniqueness of the network is that it can hold lots of different voices and lots of different experiences. Sarah spoke about the sense of solidarity at these events, and the inspiration and motivation she gets from the energy and sharing. NSUN serves as a platform to amplify voices, but what's important is how members come together, listen to each other and find solutions to the many problems they face.

Today we face ever increasing challenges as individuals and as groups, with the review of NSUN member groups in 2017 revealing that over 150 groups have closed. User-led groups are struggling to keep going and keep doing what's really important for their communities. Coming together to think about the future, and how to protect and support user and peer-led initiatives, is therefore crucial.

Sarah acknowledged the support that Mind had provided for this year's event, particularly the Engagement Team, who NSUN is working with to strengthen and promote peer support in communities.

As a result of feedback from the 2017 AGM regarding the Business section, the NSUN team appointed an Independent Chair, Cluny MacPherson, to follow members' recommendations. ●

This report includes the minutes of the 2018 AGM and a detailed record of our Annual Members' Meeting 'The Future of Peer Support'. As well as this report we have two videos available on our YouTube channel:

www.youtube.com/user/nsunformentalhealth

NSUN in 2018:

www.youtube.com/watch?v=rBnCXrKlrs0&t=365

Principles of peer support:

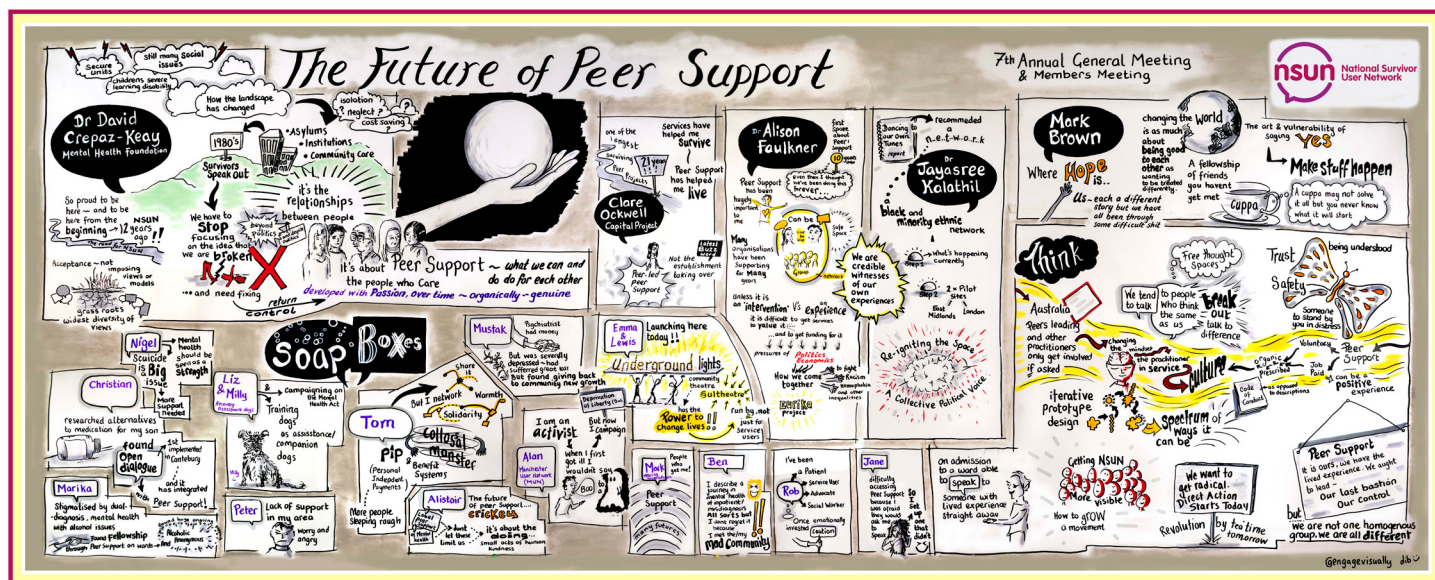
www.youtube.com/watch?v=bh6zjZanzkg&t=55

With thanks to:

flexiblefilms.co.uk

Visual by Debbie Roberts.

www.engagevisually.co.uk



Our business - Our people



► Cluny MacPherson (independent chair):

Apologies

Vice-Chair (and Acting Chair) Dr. Sarah Carr;
Trustee - Eleni Chambers; Dorothy Gould, Dominic Makuvachuma; Phil Ruthen

Item 1 – Approval of minutes for September 27 2017, AGM

Cluny asked for approval of the minutes of the 2017 AGM, as a true record of that meeting. The minutes (within the 2017 AGM report) were previously emailed to attendees and a copy was included in attendees' information packs on the day.

Cluny asked for comments and if everyone agreed with the minutes.

The minutes were approved.

Item 2 – Trustees' report (annual report) and report from Managing Director

Sarah Yiannoullou presented the Annual Report drawing attention to the summary of activity and achievements from April 2017 – March 2018. She explained the Development Project where a number of volunteers, consultants, supporters, founders and friends came together to reflect on where we were, what we were doing and where we were going. This included thinking about what makes NSUN different and unique and how we reposition ourselves in a changed environment. Sarah thanked all who had been involved in the process.

NSUN exists to make sure the voice of experience is

heard and create the collective power and influence to change things for ourselves and for others for the better. The concerns and aspirations of members have been gathered through the members' survey, events and projects and organised into the Members' Manifesto. The eight points in the manifesto steer the work of NSUN and all of our work must in some way progress these intentions.

Attention was drawn to the summary of NSUN work and projects on page 8 of the annual report. Members continue to highly rate the weekly ebulletin, members telling us that it provides a wide range of information, opportunities, campaigns and updates on health and social care policy and other developments in mental health. Many people have got involved in a range of initiatives and made connections through the information we have promoted. Feedback has also improved how we present information.

Sarah spoke about supporting and working alongside user-led and survivor-led initiatives and the hosting of projects such as the Survivor Researcher Network, Real Insight, North East Together, Kindred Minds Manifesto project and Peer-to-Peer.

Other areas of work include 4Pi, the national involvement standards. We've worked with a number of organisations and foundations and trusts to inform their work, their involvement policies and practice. 4Pi is now being used widely – both locally, nationally and internationally.

Sarah explained that the campaign work on the Mental Health Act Review had been driven by the Members' Manifesto which calls for 'reform of the Mental Health Act 2007 to make it fully compliant with human rights and make sure people are not harmed or abused'. Dorothy Gould is leading this work and had asked that people take the briefings and template letters available to lobby their MPs. There are also copies of the letter to the Mental Health Review Act panel.

After running through some of the other work areas, Sarah spoke about some of the operational challenges due to funding issues. In February 2018 the NSUN

Our business - Our people



- Chair, Sarah Carr, sent a letter to members alerting them that due to reduced core funding over the last few years NSUN's future was uncertain. It was hoped that NSUN wouldn't disappear but there was a real threat that this might be the case. The office in Vauxhall was closed, and hours and posts were reduced. NSUN has had to adapt and change and go through some loss, but it has also provided the opportunity for us to think about how we do things differently, how we work with people and how we support people to do the things that are important to them.

NSUN's work with North East Together continues but limited resources meant that not as much local work and regional development was achieved. As it's one of the things members would like to see more of, NSUN is looking at increasing partnership working with other organisations as a way of being able to do more work locally. NSUN is also a member of a number of alliances such as the Health and Wellbeing Alliance, the Mental Health Alliance and the Human Rights Alliance.

Sarah encouraged people to read the full report of activity and ask any questions.

comparatives. The surplus of £9,496 took us to reserves of £5,675 brought forward to the current year 2018/19.

Income distribution: 34% is unrestricted and 66% is restricted. Restricted funding is money that is given for specific projects, whereas unrestricted funds are also restricted in that they have to be used for charitable objectives. The main trust funders in the last financial year were Esmee Fairbairn, Trust for London and LankellyChase. Expenditure on staff costs and project costs (76%). 96% of expenditure was spent on charitable activities, 4% was spent on governance costs. The current year 2018/19 is secured. Donations raised £17,000.

Soka explained that the details for the headline figures are in the full published accounts and available on the Charity Commission and Companies House websites.

The annual report contains a summary and a balance sheet. Mark spoke about funding secured for 2018/19 and how the Board are looking to ensure NSUN is a going concern by being more creative within decreasing resources, adding that the days of totally relying on trusts for funds are probably numbered.

Item 3 –

Treasurer's Report and Annual Accounts

Cluny pointed to the annual accounts in the annual report, full copies of the annual accounts were emailed and available. He then handed over to Mark Wood (Treasurer).

Mark Wood reiterated the difficult period NSUN had gone through. However, the end of year accounts for 2017/18 were more positive than expected.

Soka Kapundu provided the headlines for the accounts 2017/18.

Income of £273,301 and an expenditure of £263,805. Figures in brackets were the previous year's

Questions from the floor

Emma Marks: I wondered if you had thought about introducing membership fees for people who had the income and were willing to pay them?

Mark Wood: Yes we have looked at membership fees. There are some big organisations who are Ally members of NSUN and who do pay an annual fee. The board is currently looking at membership options but we didn't want to make it a requirement of individual members who are often not very well remunerated. But we always welcome donations, and there are many ways of doing that which you can find on our website.

Debbie Roberts (graphic facilitator): You could have a statement when you join that membership is free but if you would like to give a donation...

Our business - Our people



► **Mark Wood:** Thank you we will take that feedback on board. Any other questions about money? (none). Thank you.

Cluny: We now need a motion to approve the Accounts for the period April 2017 to March 2018 and I need a proposer and seconder for this motion. Please shout out your names.

- Clare Ockwell proposed the motion
- Julia Smith seconded the motion
- Majority approved. No objections. No abstainers.
- **Motion carried**

Item 3 – Election of Officers and Trustees

Cluny: NSUN's articles of association require that all officers must be elected annually at the AGM and all trustees must retire at the end of their three-year term. This year all of our trustees are within their three-year term of office and so no trustee elections are required. We are currently recruiting new trustees, interviews happened last week and successful candidates will be co-opted onto the board until they can be formally elected next year.

Our current trustees present are:

- Alisdair Cameron
- Julia Smith
- Joe Kelly
- Eleni Chambers (not present)

We had three resignations this year:

- Stephanie McKinley (Chair)
- Daisy Abraham
- Dominic Makuvachuma

I think we should all say "thank you" for the time that they were able to give to NSUN. (round of applause)

Now to the election of the officers. The feedback we

had from the last AGM was that the method we have of electing trustees and officers by a show of hands, as required by our articles of association, does not allow for privacy and anonymity. However as this is the process in line with our Articles of Association it is the system need to follow for now.

We are planning to move to an online voting system but we also need to identify a suitable way to vote for those who are unable or do not wish to use online voting. We will continue to look for ways of doing this and make the changes to our Articles of Association for future voting. We will also be undertaking a more wide-reaching review of our Articles of Association to ensure that they are still fit for purpose in an increasingly digital world. So you can expect further proposals for change from us in due course. Any questions? (none). On to the elections.

Both officer positions have only a single candidate standing, so according to our rules, officers must currently be elected by a show of hands or a poll count.

Vice-Chair (and acting chair)

For the position of Vice-Chair (and acting Chair), the candidate is Sarah Carr. Can I have someone to nominate and second Sarah for this position

- Julia Smith nominated
- Mish Lorraine seconded the nomination
- Majority approved. No objections. No abstainers.
- **Sarah Carr duly elected**

Treasurer

For the position of Treasurer, the candidate is Mark Wood. Can I have someone to nominate and second Mark for this position

- Clare Ockwell nominated
- Nigel Moyes seconded the nomination
- Majority approved. No objections. No abstainers.
- **Mark Wood duly elected**

Our business - Our people



► Items 4 & 5 –

Appointment of auditors and method of remuneration

Cluny: I would like to thank our auditors, Martin Morrison & Co Ltd, for their work and recommend that they be re-appointed. Can I have a proposer and seconder for the motion that Martin Morrison & Co Ltd be re-appointed as auditors please?

- Nigel Moyes proposed the motion
- Mark Wood seconded the motion
- Majority approved. No objections. No abstainers.
- **Motion carried**

I further recommend that our trustees be authorised to agree the amount of remuneration for audit services to NSUN for this year with our auditors. Can I have a proposer and seconder for the motion that our trustees be authorised to agree the amount of remuneration to the auditors?

- Mish Lorraine proposed the motion
- Clare Ockwell seconded the motion
- Majority approved. No objections. No abstainers.
- **Motion carried**

Items 6 & 7 –

Any other business/ Special business

Cluny: Is there any other business? (none). I don't have any notification of any special business so I duly declare the business part of the meeting closed.

End of Business.

Sarah acknowledged the end of the NSUN business session and thanked Cluny for chairing what had been 'the smoothest' business session to date. She then opened the members' part of the event, welcoming our first guest speaker of the day, Dr David Crepaz-Keay. ●

Guest speaker - Dr David Crepaz Keay



Dr David Crepaz-Keay,
Mental Health Foundation

Firstly, thank you so much for inviting me to present at the NSUN AGM. It's a very special thing for me as I was one of the people who helped to set up NSUN more than 10 years ago. One of the biggest challenges we knew then when establishing NSUN was having something that was sustainable. We were fortunate to get funding to start the organisation.

In my time I have been involved in five different national service-user or survivor-led organisations, and NSUN is the last one standing. I realise just how incredibly challenging the environment is, and so thought I'd like to start by reflecting on the differences between the environment now, and the environment when I first became an activist. As that was in the 80s, there are some of you who will barely be old enough to remember.

My first exposure to an organisation of this type was the Survivor Speak Out AGM, which was characterised by the kind of factionalism that only a really active political movement can manage. I remember that just as we got to the bit where we were electing the officers, one half of the room walked out. Those leaving were the people who'd been given a diagnosis of what was then known as manic depression, and they were muttering: "Oh my God, the organisation's been taken over by the schizophrenics."

So when we talk about peer support, and when we talk about the work that we do now together as a collective group, we have come so, so far. Back then it was incredibly difficult at times to tell the difference between life on an acute inpatient ward and life with the coordinating group of Survivors Speak

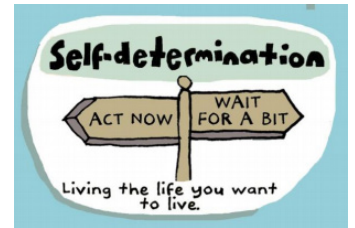
Out. The faces were very similar; the only main difference was that we were allowed to carry out our business without taking our anti-psychotic medication. You may argue about whether that was a good or bad result in the longer term, but we all felt a lot better for it.

We are not broken individuals who need to be fixed

For me this is kind of revisiting, as I do from time to time, important key stages in my life and I think where we continue to fail, and where NSUN's made such good advances and where discussions about peer support are so important is that we have to stop focusing on this idea that we are broken individuals that need to be fixed in some way, shape or form. This idea is that we have an illness, a condition or experience, or something that is inherent to us. The arguments then are: is it fixed by a doctor? Is it fixed by a social worker? Is it fixed by an occupational therapist? Or do we start to fix it ourselves in individuals?

These are sterile arguments because they still focus on this notion that we need to be fixed. The journey that I've been through marks enormous progress. It has been about me taking more control of my life. The stepping stones have been things like self-management, taking more control of how I live with hearing and seeing things, and smelling things. There's a hearing voices movement, but there's not a smelling smells movement. My kind of madness is still very much tied up with imaginary smells and it's an incredibly powerful thing.

Moving away from this idea that we have ►



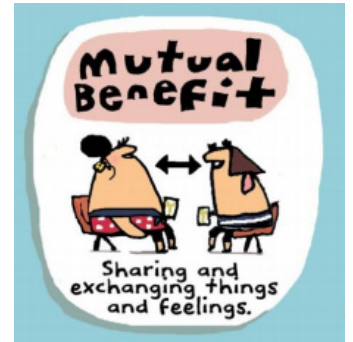
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Dr David Crepaz-Keay

Guest speaker - Dr David Crepaz Keay



Dr David Crepaz-Keay,
Mental Health Foundation



lisaholdcroft.com

► to stop, or self-manage, or be treated for those experiences - what makes our lives worthwhile, what gives us meaning, is relationships between people. Where I consider peer support to be so important is that it is the first major concept that we have created, that we have developed, that we hope is a balance. It is explicitly moving away from the notion of broken individuals gathering around diagnoses and conditions, and instead is moving towards what we can do to support each other.

Connected communities

I would argue that has almost nothing to do with mental ill health or psychiatric conditions or diagnosis - or however it is you choose to frame these things. It has everything to do with how we want to behave as a society, as a species, as a series of more connected communities. One of the most impressive things in peer support is what we do for each other. One of the most moving things I've ever been told by people involved in peer support groups is: "This is the first time I was given an opportunity to help somebody else."

One of the most damaging things you can do to a person is make them the problem that needs fixing. That is denying people the right, the opportunity to help others ... We talk about rights-based services; it is a fundamental right to be able to support and help other people, but for many, many years we have been denied that right. We have been the problem that was initially put out of sight in Victorian style asylums. I'm pleased that some of you are pleasurable young enough to have not lived at a time when that happened.

If you were just a little bit older than me you could have lived your life in one of those buildings - out of sight, out of mind, not causing any of those embarrassing issues for society. It wasn't just people with a psychiatric diagnosis confined to those institutions. People I've spoken to lived there because they had children when they weren't married, because they chose to live with, and to love, someone of the same gender. That was what passed for mental illness in some places in my adult lifetime. Still in some places today it is seen as symptomatic of being not "quite right."

Independence

So that's where we started but the key buzzword as I grew up was 'independence'. We had had these big institutions you were entirely reliant upon for the rest of your life. Then we had this wonderful thing called "Community Care" - a phrase you will be familiar with, and like anything that comes from any government, instantly distrust.

If you think of the opposite, you'll get a pretty good idea of what was going on. Community care actually meant:

"Let's flog the buildings for as much money as we can to property developers, and hope that all the mad people that we used to tell the public were dangerous are now the kind of people that we should be embracing in our community and caring for."

The idea was that it was a really sensible thing to do. I got called mad for far less damaging things than that, and I'm sure there are plenty of you in the room ►

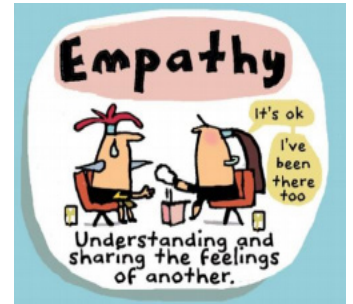
"It has everything to do with how we want to behave as a society, as a species, as a series of more connected communities. One of the most impressive things in peer support is what we do for each other."

Dr David Crepaz-Keay

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Dr David Crepaz-Keay,
Mental Health Foundation



lisa@holdcroft.com

- ▶ who've been called mad for a lot less damaging things than that.

We started to understand that it was not about moving away from being contained and hidden and dependent to being in communities, beautifully cared for and independent – because that was neglect by another name. That is still, frighteningly, a very wide experience for people now, who go through what I went through when I was 18, when I was 20, when I was 25, when I was 30 and so on. The thing that has always kept me going has been my peers, has been people who understand what it's like to be that mad thing that is me.

My peers accept my madness

Some of my favourite peers are in the room now - such as Jayasree, Alison and Emma - there are many. The fundamental aspect of peer support is that it's people who really care about me, and my madness is part of me. They may or may not want to fix it; I'm sure I'm not the easiest person to be a peer of.

I can say there are also others in this room who are not necessarily the easiest people to be peers of, but these people are absolutely what peer support is about. They are the characteristics of any decent peer support network and they are as old as experiences that were present in the Victorian asylums. One of the sad things that we lost when we closed down those asylums was that some of this stuff was going on organically behind closed walls, but it was very difficult to replicate when you just closed the institutions, and told people they had their lives back,

but without any kind of preparation or resources or ability to live what I would think of as a meaningful life.

I absolutely applaud NSUN for getting those messages out there. If we genuinely want to secure the future of peer support in a way that has meaning to us, we must remember those things are incredibly precious and cannot be taken for granted. Those of us that have lived through genuine, meaningful 'recovery' have seen that thing become a word, a brand, a logo, that anyone feels they can legitimately stick on their services and call them 'recovery-orientated' services.

I don't want to come around in 10 years' time and find that 'peer support' is now the new logo, the new brand or - even worse - yesterday's brand. To see that everyone is entitled by law to get peer support, and given a peer support worker who has recovered, and who some computer algorithm or clipboard has said is ideally suited to be your perfect peer support worker. If you don't turn up to your peer support sessions or, worse still, if you turn up to them without having taken your medication, you are no longer entitled to these services...

I get so frustrated by seeing that, time and time again, the things that we have passionately, skilfully, organically developed with genuine meaning and with genuine value, with genuine heart and soul, are taken away from us and reduced to words and brands and logos and performance indicators. That hurts me - and that should hurt all of you - because for me the future of peer support is the people I see in this room. It's people who care enough about the madness ▶

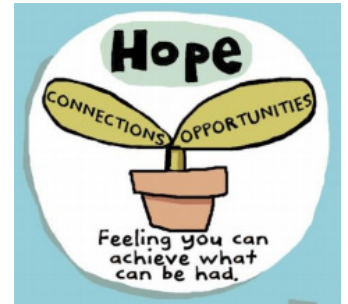
"The thing that has always kept me going has been my peers, has been people who understand what it's like to be that mad thing that is me."

Dr David Crepaz-Keay

Guest speaker - Dr David Crepaz Keay



Dr David Crepaz-Keay,
Mental Health Foundation



lisa@holdcroft.com

- ▶ within themselves and their friends and colleagues that they are prepared to come all the way to Derby, and then be proud to say: "You are my peers." Everybody should be proud to look around this room and say: "These are my peers". This is what peer support means to me, this is what we mean when we talk about the future of peer support.

Focus on peer support not austerity

We have to focus on that and not on the horrific things that are out of our control. I've never yet been to a meeting or an AGM of an organisation like this when the external environment hasn't felt vile and toxic and awful. I lived through the Thatcher years, I lived through the Blair years. I'm old enough to have lived through the three-day week, countless winters of discontent. We are fooling ourselves if we think that austerity is a passing phase or is a particularly unique piece of external toxicity. It's the way the world is when you allow politicians to have their way regardless of their colour, shape or form.

We cannot and must not rely on the end of austerity or any particular rising or falling political ideology to make an environment which is safe for us. We have to control the things that we can do. The relationships between us are far more important and stronger than that, and we should use them to fight for the things that will give us the kind of life that we want - a decent home, enough food to survive and thrive, enough food that is produced well and actually gives you some enjoyment from creating, sharing and cooking. One of my favourite pieces of peer support in the last year

was delivering cookery skills to street homeless people and, again for the first time, people were saying to me:

"I've been able to help someone else. I'm not the problem because I've got nowhere to sleep, I'm part of the solution because I can cook a meal for my friends."

That is precious, that is peer support, that is where the future is. We can do that with the power of what's going on in here.

I would love to have a magic wand and say let's have all the resources that we could possibly need to do this properly. I would love to be in the position where we no longer have these futile, facile arguments that there is not enough money going into mental health services. You look at some of the money that's going into keeping people locked up, there's plenty of resources for that. We need to continue to work on the peer support that we want, the future that we want, and we have to genuinely believe that it is in our power to achieve it. ●

"One of my favourite pieces of peer support in the last year was delivering cookery skills to street homeless people and, again for the first time, people were saying to me: "I've been able to help someone else. I'm not the problem because I've got nowhere to sleep, I'm part of the solution because I can cook a meal for my friends."

Dr David Crepaz-Keay

Comments from the floor



I. Alan Hartman,
r. Christina Young

Alan Hartman

Trusts professionalise peer support and make it into a service - that's what's happening in Manchester. I'm a generation before you and was a member of the Mental Patients' Union. When user involvement came along in the 80s, one thing that grew from peer support was peer advocacy. What organisations do is take away the things that give you rights like peer support and make it into a service. Ironically there's been service users kicked out of peer support groups because they won't do what the organisation wants them to do.

We have to really activate our rights. In the 70s and 80s we didn't know the word 'peer', but we were aware of peer advocacy. We made friends, and went out, went to the cinema, we'd talk about medication, which was then horrible. A lot of my friends are now dying young because of the medication. We really need to get together and help each other, we need to keep going and I want to help my fellow man.

Christina Young

I absolutely agree about peer support. Yesterday in a survivor history group meeting, I picked up the excellent 'Asylum.' There was one of the best articles I've ever read by Akiko Hart, "Pursuing choice, not truth: debates around diagnosis in mental health." I'll just read one little paragraph:

"I find, and I am pained to say this, that there are at times more similarities than differences between those who believe vehemently in the biomedical model and

those who are compassionately against it. Most people don't live in either of these camps - they have the most nuanced views about the validity of different diagnoses, or on the different impact they can have on our lives."

Akiko talks about polarised debate and says that we can't just say medication or pills are right or wrong, good or bad. For some they are life-saving, for some they are life-ending. She finishes by saying that a good thing would be a system where the language of illness might sit side by side with the language of trauma, where we talk about the biological causes of mental illness as well as the social causes of distress. As somebody who had my life changed by both medication and self-help groups, I found benzodiazepines to be absolutely invaluable in aiding my recovery if I managed them myself.

When I was young, I did take a lot, but I had no problems stopping when it was me who decided, not the doctor. I had no withdrawal symptoms and very occasionally I still take one. At the same time I'm also in an excellent women's self-help group in Liverpool.

I do not like to have any model imposed upon me. I want to choose my own model and I don't see the models as mutually exclusive: social model, illness model, medical model, spiritual model, whatever you like to call it. I see them as being integrated for me, and it's for the individual to choose. Please give us choice, allow us choice. Our voices aren't heard very often in the user movement if we say we've been helped by pills but it is about choice and, as NSUN says, the voice of individual experience.



"We made friends, and went out, went to the cinema, we'd talk about medication, which was then horrible. A lot of my friends are now dying young because of the medication. We really need to get together and help each other, we need to keep going and I want to help my fellow man."

Alan Hartman

Comments from the floor



Ben Glass

► Dr David Crepaz-Keay

I hope we'll talk later about the nature of peer relationships. A really good peer support group will bring people together who share those values. I was one of those people who was never helped by medication, but I know people who have been.

I think the issue of diagnosis is a more complicated one. It's useful for some people. While I have yet to come across many people who find the diagnosis of schizophrenia valuable and meaningful, I come across plenty of people who find the diagnosis of bipolar valuable and meaningful.

I think choice is an interesting concept. It means different things to different people and I think making informed choices is important but complicated. I feel very nervous for those people involved in the Mental Health Act review at the moment because so many people are interpreting things in so many different ways. I've heard people talk about the right to medication - but they're psychiatrists talking about the right to medication, the right to prescribe medication. I don't see that as a fundamental human right. However, I'm not a human rights worker, nor a psychiatrist, so neither of those groups are my peers.

I grew up at a time when choice was a kind of very Thatcherite thing and so I have a slight nervousness around the word choice. I'm also almost clinically indecisive so the one thing that is almost always guaranteed to paralyse me is too much choice. My peer group may well be made up of decider folks who work out a new and better way of working out what they want for breakfast - that would

be an immensely useful support group for me. None of that is contradictory to the values of the Peer Support Charter Principles, which talk about trust and diversity, about empathy and solidarity and self-determination.

Ben Glass

I'm really glad the two speakers before me brought up the points about community, and the issue about models and non-inclusive models. If we start deciding as activists, as campaigners, as revolutionaries, (whatever you want to call us), what the right model is for understanding the stress, illness, disability, madness (whatever you want to call it), we are really doing our community a massive disservice for two reasons.

Firstly, when we impose an ideology or model - and say this is the right model or this is the wrong model - we're stamping on the grassroots, on the wards, in the day centres, the drop-ins, people's homes, where people are isolated. In the discussions online and on social media, you get a whole panoply of views on what works for individuals and what's right for them.

Secondly, it is a problem because of our weaker position socially, which means we end up being foot soldiers for interested groups, which is kind of what Akiko Hart was hinting at in that article. We'll end up being the cheerleaders or foot soldiers for this or that set of professionals, with this or that set of their own ideologies.

That takes us back to community. On the wards, in the day centres, in the drop-ins, in the asylums, it's us that creates



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"A really good peer support group will bring people together who share those values. I was one of those people who was never helped by medication, but I know people who have been."

Dr David Crepaz-Keay

Comments from the floor



I. Speaker 5
r. Rachel Rowan Olive

► that community; it's not done for us, we create it. And obviously that's much harder when you're isolated. With the advent of social media, it's changing. I don't know if it's getting better or getting worse, but it's certainly changing. It's us who are creating that change and when you see that community in the grassroots, then you will get peer support which isn't diagnosis-based.

If you go to a day centre or a drop-in, you don't have your peers telling you what you should be doing, or what your diagnosis ought to be. You don't have an ideological diagnosis which is wrong - medication is wrong - you get far more organic, fluid conversation and support and solidarity going on.

Finally, I'm really glad you brought up asylums and the risk that in the modern movement we forget them, and see them as a romanticisation, if that's the right word, of pre-psychiatry under the priests and shamens or whatever. I think now we're seeing a romanticisation of asylums, of institutions, as we're afraid of going back to being locked up for our lives. In fact we still have asylums in this country, they haven't gone away - if you've got a diagnosis of autism or a learning disability you could find yourself locked up for decades. I know someone whose son has been locked up in an assessment unit for 19 years. We have 250 children in this country who could live in the community but because the CCGs and the local authorities are duelling it out over who should pay, they're locked up for decades in assessment units where children are being fed through hatches. Asylums are still here.

Speaker 4

Going back to the idea of informed consent, the myths of medication and ECT are being debunked by the very hard work of a lot of people. It's really important that those issues are top priority in discussion of medication versus psychological or social approaches. Getting that information is hard and I think it's appropriate for organisations like NSUN to be at the forefront for providing information which is often concealed.

Rachel Rowan Olive

I can really see the value in the idea about moving away from broken individuals but I also think a lot of the time I do feel broken, and it matters to be able to have space to say that. I've got so much that I've never got from the system from the solidarity of other survivors and ways of understanding myself from other people's experiences. That's so valuable to me but it's also really hard supporting each other when we're all struggling at different times, sometimes at the same time. I just think it's really important that the future of peer support doesn't become just carrying all this extra weight just because nobody else is there to do it. I'm angry about that.

Mustak Mirza

I'm from Birmingham West Midlands Service Users Foundation Trust. I sit on interview panels but we don't influence, only 10 percent. Peer support workers should be paid according to what they do and how experienced they are, not just to do a rubber stamp exercise. It's your lived experience that matters, we need to celebrate our own lived experience. ►

"...it is a problem because of our weaker position socially, which means we end up being foot soldiers for interested groups, which is kind of what Akiko Hart was hinting at in that article. We'll end up being the cheerleaders or foot soldiers for this or that set of professionals, with this or that set of their own ideologies..."
Ben Glass

Comments from the floor



Nash Momori,
Founder of Real Insight

► Nash Momori, founder of Real Insight

I suppose as much as we need to have choices, peer support should be genuine and real, that is what matters. I'll give you a good example. Setting up Real Insight four years ago, we were hosted by an organisation that was very reputable, yet the communication was so bad, it was really difficult for us to carry on, and so we had to stop.

Now being hosted by NSUN has given us the most peer support we've ever had. We're both user-led organisations, we've communicated on a level where we've understood each other, we spoke similar languages and we have the same tone. Moments where I felt broken, where I couldn't cope, and it was midnight and I wanted to give up - I could pick up the phone and call Sarah who's my host director. She was able to hear me and support me, even though it was out of hours. In the same way, we need to be able to empathise and understand how our peers are feeling. I might not be able to help someone but if I share my experience it might help to explain how I cope.

Dr David Crepaz-Keay

Everything that everyone has said resonates and I don't think there are any contradictions between these complementary views. I think one of the most impressive peer support groups I worked with was definitely made up of people that would describe themselves as broken individuals. I really would recognise exactly the picture that you describe.

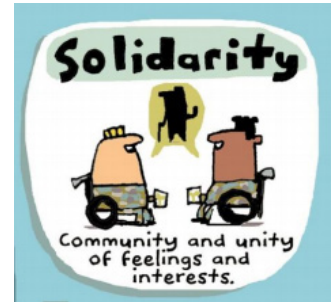
I think the word I would use to replace

'choice' would be 'control' because I think one of the things that made a difference for that group was that they as a group invited community pharmacists to come in and talk about different kinds of drugs, and that helped them make informed decisions. They also invited a really good sleep therapist to come and talk about how you can get a good night's sleep. That was such a big difference from their experience of going to their GP and being given sleeping tablets, to have someone who is an expert in sleep come and talk to you as a peer group, bring their expertise and say well actually there are lots of ways that you can try to get a good night's sleep. Try these, and see if they work for you, before it gets medicalised and turned into a clinical disorder.

I think that's this kind of locus of control that used to sit with the head of the asylum then, come the purchaser-provider split, the governance boards of the NHS Trust. It's really very difficult to work out who controls what now. It's still the case that if you have my diagnosis of schizophrenia, it takes 25 years off your life expectancy - that's not a great thing to be to be living with. Those are the kind of things that we need to be addressing so that we can take control of our lives back and live decent long and fulfilling ones.

Sarah Yiannoullou

Thank you so much, David - fantastic that you could be with us today, and we really appreciate your continuing support. Now I'll invite Clare Ockwell, CEO Capital Project, to speak. ●



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"I could pick up the phone and call Sarah who's my host director. She was able to hear me and support me, even though it was out of hours. In the same way, we need to be able to empathise and understand how our peers are feeling. I might not be able to help someone but if I share my experience it might help to explain how I cope."

Nash Momori

Guest speaker - Clare Ockwell



Clare Ockwell,
CEO Capital Project
and NSUN member

I call myself CEO-come-general-dogbody because that describes my job much better - so don't be intimidated by the silly job title, please. Capital is a peer-run charity. We are quite privileged as a peer-led group in that we've actually existed for 21 years. I was a founder member, and Capital has turned me from mouse to mouthy, so that's the journey that peer support has taken me on.

Nobody talked about peer support 21 years ago. While I've used services for 51 years, and I was very, very young when I started, I've only really started getting involved over the last 21 years. Nobody empowered me to get involved before and I was the sort of person who thought I ought to be grateful to services for helping me. Yes, they helped me survive, but peer support has helped me live - and that's a huge difference.

At Capital we do offer formal peer support services, which sounds quite scary because our Mental Health Trust also runs formal peer support services that are people who read and write people's notes, and do things like that, but to me that's not peer support. We have inpatient peer support workers and yes, we do pay them, and we often pay them a lot of sick pay because it's hard work and they're not as fully recovered as other groups people might consider employing.

They're people on their journey. I'm not sure I'm as fully recovered as a lot of people would consider employing, but that's a whole other debate. But there are people who have been there, done that, got whichever t-shirt they want to wear, because we're all so different and are prepared to go and say: "Yes, I've been

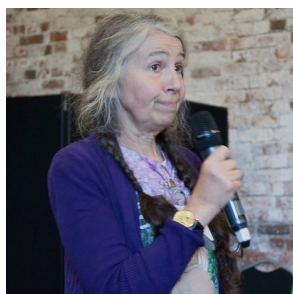
there, done that, and so perhaps I can help you. Perhaps I can show you there is life beyond the revolving door of being in and out of hospital that so many of us have probably been trapped in at some point in our lives."

Peer Support Charter

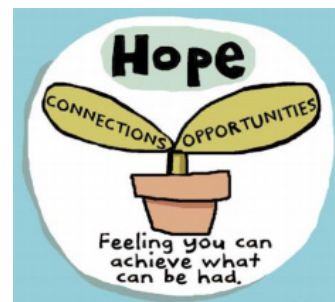
Recently we've been involved in developing a Peer Support Charter. There are copies on the table. Some people might think of the labels like solidarity and commonality, as jargon and that's fair enough. I think of it as jargon, particularly commonality, but I sort of know what it means.



"Nobody empowered me to get involved before and I was the sort of person who thought I ought to be grateful to services for helping me. Yes, they helped me survive, but peer support has helped me live - and that's a huge difference."
Clare Ockwell



Clare Ockwell,
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and NSUN member



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- But this is a charter about some principles, it's certainly not a 'how-to' charter because I don't think there is any one pattern of how to do peer support, and that is the richness that some of the earlier questions and comments have shown. We are such a diverse group and so what we will want and need to support each other is going to be very different. What helps me may, or may not, help anyone of you in the room. What I would like to see in the future is some kind of menu of peer-led peer support. I am scared of the establishment taking it over from us, I really am, and I think it's happening more and more.

There should be a menu of the different types of peer support, and that can be whatever is important to you. It may be about your gender, your race, what you enjoy doing in your spare time; it may be about anything that gives you that common link with your peers that helps you, and helps you build. For me, when I joined what was then called "Users and Trainers," now the Capital Project, I didn't believe in myself. I didn't see anything in me that could be useful to anybody else but my peers around the table saw it. Because I was a little mouse, I had a little voice, but I couldn't travel around to use that voice - but people helped me.

Mouse to monster

They came along, they sat beside me and they would read a book, or do their own thing, while I stood up and said my piece. Then they'd help get me home safely and without that I would not be the monster I am today. I want to be a bit of a monster because sadly we need to be monsters, we need to be strong and stand up and hold out for what we need, not what society takes on.

Peer support is the latest buzzword, let's not shy away from that. The NHS has grabbed on to peer support and wants to make it their own, so we have a fight on our hands. I think every one of us in the room has things to say which are as valuable as any one of us who has been invited to speak. I want to hear from those voices, and I would like to apologise to some of my wonderful peers that I won't be hearing this afternoon, because I do have to get home and fulfil caring responsibilities.

I'd really love to hear what Jayasree and Alison, and everyone else has got to say because it refreshes me and re-empowers me. There are days when I need that. I may stand up here and say something today but last week there was a day I when wanted to chuck it all in, give up, go home. But this sort of thing re-energises me, and we all need days like this so much. ●

" I may stand up here and say something today but last week there was a day I when wanted to chuck it all in, give up, go home. But this sort of thing re-energises me, and we all need days like this so much.."
Clare Ockwell



I. Christian Sestier
r. Liz Maitland, Recovery
Assistance Dogs

Christian Sestier

I am the father of a son who was diagnosed with psychosis two years ago. I started researching alternative approaches to the medication that was developed for him, although I think for my son medication has been useful to a certain extent. For two years now I have been researching Open Dialogue. It's a Finnish initiative featuring an approach they use there in cases of psychosis.

There is evidence that this approach is effective, evidenced by some research which showed that more than 80 per cent of people with psychosis returned to work after five years. That led to a grant from the National Institute of Health Research to try this approach in the UK, where it is directed by Steve Pilling from UCL. It is managed by the North East London Foundation Trust with Russell Razaque. I live in South West London, so my Trust does not participate in the trial.

I tried to see how I could advocate for this approach to be used in my Trust and had the opportunity to find a person who was a keen advocate of Open Dialogue. It started like this: Joe Jackson, deputy lead of Wandsworth Early Intervention Service, organised three days' training with a presentation to all the members of the Early Intervention Service, Home Treatment team, the families, some of the psychiatrists from the Trust which was a great success. Following this success, we had the opportunity to visit the first implementation of Open Dialogue in the UK in Canterbury with Yasmin Ishaq. Following that, an Open Dialogue special interest group opened in the Trust. Interestingly, what they did in Canterbury was to integrate peer support with Open Dialogue, making it peer supported Open Dialogue. I really hope this will develop and I think it is a way forward for the current system.

Liz Maitland, Recovery Assistance Dogs, with her Assistance Dog, Millie

How many of you in the room have dogs? Those that do know as well as I do how brilliant dogs are for wellbeing, they're absolutely fabulous. We're a charity that was set up in 2004 by survivors of mental health problems. I myself am a survivor of mental health problems.

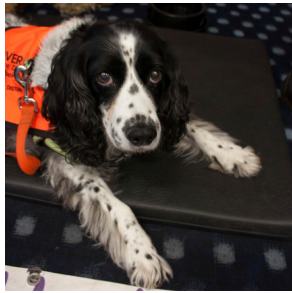
I've had 23 years in and out of hospital and I relate to David Crepaz-Keay, as I was diagnosed originally as a schizophrenic. The truth couldn't be further from that, because I didn't have any of the symptoms - they just called me that basically because they couldn't believe what I was saying. I just had a really challenging life for 23 years.

Over there is a puppy we're training for a client. The charity was first of all set up about 14 or 15 years ago. We set up to campaign for freedom against force and fear. As a human being I have a right to freedom and a right to a fair trial before being locked up. We've always felt that people should only be locked up if they're a danger to themselves or others because that's the law. We believe that if there's a court case to protect people, then first of all people should have a right to choose, because most of the time people are locked up for far less - and when they're not really ill.

Most of the time psychiatric hospitals will only lock people up if they're not feeling suicidal. If we thought a court case would help the person to get the support they needed when they're feeling suicidal, and they really are a danger to themselves - or if they are a danger to others - then the court would make sure the person can find a bed. How many times was I locked up when I was about to go back to work? I was a trained teacher, so I had a good job, but they used to lock me up. Yet when I was suicidal and trying to kill myself - which I did on five occasions - they wouldn't speak to me.

I thought there's something wrong with that. As a result, every Saturday we'd go all round the country talking to people about the court case. Everyone has a human right to a fair trial before they're locked up, so they're not being locked up unnecessarily. Theresa May agrees with us, and that's why we got the review. We filled in the review and the survey, and we made it quite clear that people should have a court case with lawyers involved. So that's what we do, as well as training dogs, so if you're interested in really recovering completely from mental health problems - which I have - my dog Millie is far better than any husband.

She sleeps with me, and she never answers me back, ►



l. Millie
r. Tom Griffiths

▶ and never tells me what to do. She's brilliant, and since I've had her I've not felt suicidal once - that's one year - and it's been really great. I also noticed that working in a secondary school is about the worst thing for mental health. A lot of teachers have mental health problems and dog training is a great therapy. So if you have a dog, and you want to have it trained to help your recovery, then come and talk to us because we've got about 300 clients whose dogs we help to train. All of the 120 people who engaged with us last year kept out of hospital, and their dogs are really helping them to keep well.

Tom Griffiths

I'm a gentleman who wears different hats, but not only as a service user. I'm proud to be chair of a group in Manchester called Manchester Mental Health Charter Alliance, which is a group of people who come together - service users and carers - to give people a stronger voice in their health services. And the question I'm going to raise today is "Does this make a difference?" We're in the middle of a process in Manchester of challenging decisions to close centres, developing systems that the professionals are saying is helping people to get recovered and step people down, all this sort of stuff - we're trying to make a difference. I'd be interested if anybody else across the UK is involved in something similar where they've got some token legal role within the system and they're chipping away and want to do it better. I'd like to learn how we can do it better as a charitable alliance.

One of the hats I'm mostly wearing is community advocate for people who are facing PIP/PSA bids. This is linked in so many ways to the issue of peer support, and the lack of support that people have, if they are disabled or mental health service users. There's a discussion about the relationship between the two. I could give so many examples of people just being cast aside. I can't speak quite as powerfully from the heart as some of you can, but I've seen it and I've witnessed it - people sleeping rough in Manchester, people who are forgotten and lost - and people die because of this combination of things.

What can we do to improve things?

What can we do? Because you're challenging a big system out there, you know it better than me. Professionals can redefine terms used in moral concepts, whether that's peer support, whether that's recovery, whether that's even community care going back 20 years. They've got tens and thousands and millions and billions to justify what they're doing. How can the state give genuine peer-led peer support - that is genuine peer support in terms of supporting disabled people and mental health service users, who feel victimised by the benefit system? I'm part of something called the national network of community organisers. We met just last week in Stoke to see what could we do with that network, just in terms of people facing welfare appeals or universal credit difficulties and sanctions.

I'd be pleased again to put them in touch with listening to your stories, and would ask are there connections to be made? I'm really raising questions here, not answering them, but there is a social solidarity within a movement of people here who recognise what a well-financed monster we're dealing with. I like the idea from someone earlier that we have to be scary monsters too, super groups. So how can we have some solidarity going?

Today's great, it's fantastic, and it's a privilege to be here. It's my second time but there is some extra solidarity. We can work together, and we want to do it better, we know we can do it better, but it's very hard as we're all volunteers. I'm a volunteer, and I've got other things to do, including trying to fit in issues with PIP and Universal Credit. That's why I'm asking if there's anyone out there who wants to tap into some greater national solidarity on those issues, as it would be fantastic. I feel a warm and friendly buzz, that I want to take away with me. I might get a little bit depressed on the train home thinking where's this feeling of solidarity going, and wondering how we can retain it for all 365 days in a year, not just one day.

Alan Hartman

I've been a service user for 48 years and, like David, I've had so many diagnoses - I think it's about 10 now - and I have become an activist. When I first got ill, I wouldn't



l. Alan Hartman
r. Mustak Mirza

► say boo to a goose, and they pumped me with drugs, and I didn't know how to hit back. Then I learned how to hit back, but then I got violent, and was under for three days with drugs. I'm an activist, and it's what you do, not what you say, and not just around Manchester, not just Greater Manchester; there's so many people now being excluded from help and support.

One of the things I want to make people aware of is in Greater Manchester, in our Trust, Greater Manchester Mental Health NHS Foundation Trust. Firstly, they ignore everything that service users say, and they've got a new strategy which is saying if you don't use the service in 12 months, you're no longer a service user. That means you get no support. Going back to what Tom was saying, you can then get into trouble with benefits. What is so ironic is that the service is so bad you're lucky to see a nurse or psychiatrist in 12 months. Trusts copy Trusts, and it's very serious. For people in Greater Manchester, we're having a meeting at the Charter Alliance to see what action we can take.

Section, prison or care home?

There is another thing that is also very bad which worries me. I was elected to go over to Trieste in the 90s, when they said they'd done away with sectioning people. I was really happy about that but then a nurse took me to one side and said: "Alan, it's not what you think. We put them in prison instead." That is what worries me. If you are a risk to yourself or others, and you get off the section, but you get put in prison.

I'm in my 70s now and there's another thing that also worries me: Deprivation of Liberty Safeguards (DoLS), which is worse than a section. They can get you into a care home on DoLS, and they can hold you in that care home without an assessment, and you could be there for ages, depending on how long you've got to live. You can't go out, you can't do anything, and it's all about making money for the people that run the homes. I need to make people aware of it because things aren't getting better, in fact they're getting worse – locked wards – and it's really going backwards. We need to be stronger and we need to be more militant.

Mustak Mirza

I wanted to talk about my own recovery but after hearing the lady with the dog, I'm going to tell you two stories instead. This person was having a life crisis, his wife and children had left him, so he became very isolated and lonely. He didn't know what to do so the doctor gave him all these drugs, but they weren't working. He decided to try to rescue a dog. He brought the dog home which meant he had to get up in the morning to take the dog for a walk. He said basically the dog rescued him, giving him a purpose to get up for. By giving something you often receive more, which I've believed my whole life.

Then there is another story about a lady sitting on the psychiatrist's chair. She says she's not happy. She says she can buy anything but she's not happy. The psychiatrist asked her to wait and brought in another lady.

The second lady said that six months ago she lost her husband, and three months later she lost her only child in an accident. She said she came home depressed and anxious, when a cat followed her into the house as she opened the door. The cat curled around her leg, which made her smile – and that was the first time she had smiled in six months. After that happened she baked a cake for her next-door neighbour and says she that she now keeps giving to society which is why she keeps happy. I follow that ethic – give something and receive something back.

Emma Ormerod and Lewis Ford - Underground Lights Community Theatre

Emma: I used to work for NSUN, so most of you probably know me, but you don't know this gentleman.

Lewis: I'm Lewis and you probably don't know me because I've never worked for NSUN. We're here to launch our theatre charity, Underground Lights Community Theatre.

Emma: We want to talk about theatre and about how drama has the power to change people's lives, which we both know from our own personal experience. When ►



Alisdair Cameron,
NSUN Trustee

► I was 16 I wasn't in a good place at all but a community theatre project in Exeter provided the glue that kept my pieces together for quite a long time. It certainly did me a lot more good than all the drugs the NHS were giving me.

Lewis: I agree. I was homeless for a bit after I left school. It was two years of awful, and always declining, mental health until I saw on the timetable of the homeless charity Crisis Skylights some drama classes. They were being run by Emma, and I started volunteering there in my second term, which changed my life. I started to see how it was changing other people's lives too, and so when Emma mentioned she was leaving Crisis to set up her own theatre charity, and asked if I wanted to come along for the ride, I couldn't really say no.

Emma: We are based in the Coventry and Warwickshire area and are very much looking for supporters. Follow us on Twitter or come and talk to me if you want to find out more about the work that we're doing. We got a little bit of funding from the Heart of England Community Foundation in January 2018, which is really great news. We don't just want to be here to run activities and run workshops for our members, we want to be member-led and member-run, so that's why we wanted to launch the work here at the NSUN AGM. We would also like to thank Sarah Yiannoullou, who gave us so much support in the early stages of the set-up and we'd like to thank Kirk Teasdale, who designed our logo - both of them have been brilliant.

Peter Rawlins

I'm from Macclesfield, and this is my first time here. My story is about my partner, Cathy, who has had a horribly depressing time. She had her children taken away after the breakdown of a relationship. I've known her 27 years and my point is that there doesn't seem to be a lot of support in my home town and I feel very aggrieved and emotional about that. I met Cathy by chance, and we've been married now for four and half years.

This is the first time I've come to Derby, although my grandfather actually worked for Rolls Royce and my Dad is from Derby. My partner gets very upset when I leave

her alone and I did explain I was coming to try and get her some help. I was very heavily involved with Mind in the 90s and left when I fell out with the management and the way they were running things. It became more of a drop-in, rather than an organisation to help people, and I became quite aggrieved about that. A friend of mine who has been in hospital has helped me a great deal. He's out at the moment, and reasonably stable, and was well enough to be my best man. Other things have helped me, and Cathy herself has been a great help to me.

My main point is about the lack of peer support. I'm a reasonably well-educated man but I feel powerless to help her. Her mother has spent her life savings trying to get a guy who sexually assaulted her. She gets very emotional because she doesn't have access to her children. I'm a full-time carer for her. I did have a job. I'm just trying find help for her. She isn't under a mental health worker and she's wrongly had her children taken away which makes me very upset. It's lovely to come here and get some help and meet so many nice people and I have been enthused by it.

Alisdair Cameron, NSUN Trustee

So what's the future of peer support? In some ways there is no future for peer support. I say that because I share the fears expressed by Clare, David and others that no matter what terminology we use, it's going to be adapted, co-opted and it's going to be twisted. There is an issue there that once you put a label on something, you run a real risk of limiting it. We started today by saying this is peer support, then we started thinking but this is not peer support. There is something which a lot of people have touched on already, about making sure it's not about the labels, because there's an issue about labels in any case. This is an issue about being defined by other people, about being defined in terms of your relationship to services.

We use the term service users and inherently that is the notion that: a) there is a service and b) we're able to use it. It's also defining us by means of a relationship to something that is external. The key message that I've taken from this morning is that it's all about the doing, ►



l. Nigel Moyes
r. Ben Glass

- ▶ it's not about the labels. It's not about the talk, it's about being there for each other in a reciprocal fashion and just looking out for one another. It doesn't matter what label you want to put on it - put one on it if you must - but be aware that the label is going to be taken and used by those who have more power.

That's the nature of power: power will seek to find ways that suit power structures. That leaves us with the situation of it getting away from debates which are not on our terms - looking out for one another, lots of small acts of kindness - but also even getting away from the notion of mental health. This is about us as human beings. Other people will define us by our mental health problems but that's not who we are. We may have this mental health facet to our beings, but that's not the be-all and end-all of us. We are looking out for one another in all of our glorious flaws. There is a future, but let's not call it peer support because that will end up limiting us, it's really about togetherness.

Nigel Moyes

I just want to give you my spin on peer support and men. In my home county of Suffolk I've been involved in a project called the Twelfth Man project. There was a need for it because suicide is the biggest killer in both young men and men between the ages of 45 and 55. I happened to be a white male at the age of 55 before going into the mental health system, and I came through the other side, but there wasn't much help for me, being a man, looking for support. Getting involved in the Twelfth Man project helped me to be with other males, and just be human, and talk about those everyday things that seem to be lost in today's society.

I'd also like to share that I lost my father in May this year at the age of 91. He came out of the national forces in 1948, which was when the NHS was started. He went to see his doctor because he had suffered a bit of trauma and his doctor said: "Here's a pill now go away and sort it out yourself." I'm proud to say that as a survivor I will continue with the values of my father.

I just want to leave you with this: mental power should be seen as a strength and not a weakness to be talked

about. As Alisdair said, I think we should look at the concept of peer support in a different way. However, going forward, suicide is a big thing and there needs to be more support around it.

Ben Glass

I'm a really proud person, in a good way, in that I'm proud of being me and I'm proud of being mad. Because I'm proud I don't really like apologies, I don't really like giving apologies, although I can bring myself to do it. I really don't like getting apologies either, especially those NHS apologies you get: "We're sorry for how you feel," or "We're sorry that was your experience." Oh f**k off...

I am also a hypocrite because I'm about to apologise three times now. Firstly, I'd like to apologise for saying things that everyone here already knows. But perhaps I need to apologise for making assumptions? I think as a community there are some things that we don't know. I'd also like to apologise for being smug.

The reason I feel smug is that I've been in the mental health system since I was a child. It began with a misdiagnosis of schizophrenia with an illegal Mental Health Act detention. That was 14 months in a mental hospital, and for most of that time I was sectioned. For half a month I was in an adult psychiatric intensive care unit (PICU), where I was assaulted twice. 15 years later, they decided I wasn't schizophrenic, but no apology, no acceptance. I then had to come off all the medication I had been on since I was a child by myself, with no support. That's the way it is. That was after 20 years of just being treated like I'm a monster, like I'm not a person, like I'm not worth anything.

But I don't regret that for a second: firstly because I really do like fighting the bastards, and I'm in a really good position to do it. I actually feel sorry for the social workers and the critical psychologists and the academics and the activists because they're doing it from a distance, and I like to be able to do it upfront. But the main reason that I don't regret it is because being in the mental health system meant I got to be part of a community.



Rob Gough

- ▶ I don't know what to call it: the mad community, the mental community, but it is an amazing community. People mentioned warmth earlier, and that warmth I always feel when I'm around other mad people and other patients, other survivors, other service users. I haven't been in a single ward, in a single day centre, in a single drop-in, any online space, any meeting that has not been characterised by solidarity, by endless support for one another, by the sharing of advice and experience. The thing is though, we know we're shat on, we know that our bodies don't belong to us, that our privacy is violated, that we have to beg for support, that we're lied about, that we live under the dictatorship of other people's subjective whims and subjective opinions.

We all know that but mainly I don't think we know as a community how f**king great we are. I don't think we have the pride that we deserve to have. I don't think we realise that the community that exists everywhere we are, and the reasons the services keep going, is because of us. We've been here for millennia; we were here long before the psychiatrists and the nurses and the doctors and the therapists and the imams and the priests and the rabbis. Before all of them, we were here and we will be here long after they've all gone, and it will be us and our strength and our courage and our sheer f**king ferocity that will make this world a better place.

Rob Gough

I'm from Penzance in Cornwall which, relative to where we are here, feels very, very remote. One of the things I find so awesome about being here is the number of people present, and the active engagement between the audience. I find it really, really inspiring. I've been a service user, I'm a survivor, I've been a mental health practitioner, I've been an advocate, I've been a mentor and I'm acutely aware and really, really excited about the potential for peer support.

My background is in psychology and I've got a very keen interest in human behaviour, (don't worry, this isn't going to be an academic debate), and particularly what happens in how our behaviour changes once we have an emotional investment in what we are doing, and once we start to feel pressured by anything.

That interest comes out of a really profound experience I had a few years ago in peer support but not working within a formal network. When I was walking away from a meeting that I'd had, a discussion about recovery that I'd had, with an acquaintance of mine, I had this amazing feeling in the back of my mind that there was something wrong.

Emotional investment and process

I looked at it more closely as I was walking home and I felt a moment of alarm that I was in danger of starting to use exactly the same sort of very, very subtle coercive behaviour and practices that I myself had found so upsetting and distressing with some of the mental health practitioners I'd worked with.

I had to be honest with myself and realise that I was starting to do exactly the same thing with this person who was on the same sort of recovery journey that I was. My emotional investment in that process, and my beliefs about what I thought needed to happen, had started to lead me unwittingly to put pressure on the process.

I've worked with some mainstream mental health practitioners who have been really supportive and understanding and, crucially, understood how important the processes are when we're working with other people. It's not just what we're doing but how important that process is to feeding in to what we're doing. As I walked home that night I said to myself very quietly: "Rob, you are drifting into making exactly the same mistake that you found so distressing with the practitioners that you worked with."

I share that with you because for me one of the dangers that I have to watch out for as a peer supporter and a peer mentor is that the greater the emotional investment I have in what I'm doing, and the more pressures I perceive, the more I am also susceptible to starting to indulge in that kind of coercion. Peer support has huge, huge potential. I really believe that as long as it doesn't become some kind of tacky trademark, in the way a number of other people have suggested. I do believe that one of the great difficulties we have is to deal with



Jane Salazar

- ▶ that and address it. It would be really good to hook up with some of you guys, particularly those of you who are actively doing stuff, because one of the difficulties I have when I go back to Cornwall is once again that horrible feeling of remoteness.

Jane Salazar

I have a lifelong history of selective mutism, so if I go silent you can take that as a cue to go for lunch. A bit about my background: with my selective mutism I found it difficult to access services. That may have been a blessing in disguise, but I was also unable to access peer support. I knew that when I went into the room they would want me to talk, and it wasn't going to happen. I thought why am I actually waiting around for somebody else to do it - so I decided to start my own group.

I now run one group in Kent and a second group in London. I also want to bring to you today a project that I'm currently leading, or starting, about finding the voices and amplifying them, which Sarah Yiannoullou mentioned earlier. Sarah also talked about community peer-led groups and said 160 groups have closed down.

So far we've had two larger meetings and a smaller meeting, and this project is about a new space: it's a space that's very community and peer-led. It embraces all the pieces of our history and kind of folds them all together to share commonality. The interesting thing about it is it's also a space that remains curious - so it's time for us to explore, to share knowledge.

Get Up Set Up

It's full of courage because it's actually quite complex and quite messy. There's a lot of uncertainty about actually having a space to work in and I think along with that comes the ability to actually show your vulnerability in that space, to show your courage. There's an acknowledgement of building around support within that space for all these voices we want to amplify, who are driven by community-led peer support, to come together. It's now called: "Get Up Set Up," which isn't quite as direct as 'Sod It,' which is what I originally wanted to call it.

I also wanted to say something about that branding. Someone sent me a message to say, 'why are you upset?' If you start playing around it's like 'Get Upset'. Someone else said it's like one of those puddings - 'Gusu'.

We're hoping to have three strategic meetings this year, narrowing down the direction of where we're going. We want to be very transparent about what it is, what it is not, what we can offer, and what we can't offer. We're currently supported by Mind, but don't know whether that will continue, but we're quite happy there at the moment.

We will see what the future holds. ●

Guest Speaker - Alison Faulkner



Alison Faulkner

The first time I spoke about peer support was approximately 10 years ago in Nottingham, at an event organised by Making Waves, which some of you may have heard of. It was a wellbeing space where people were encouraged to talk critically about peer support and recovery. It was at a time when peer support was becoming this new thing, intentional peer support was this new thing, and I was thinking I don't understand - because surely we've been doing this thing forever? That was one of the first times I had the opportunity to talk with people about how we think peer support is for us, versus how services might be beginning to incorporate peer support as an intervention for mental health.

Peer support was hugely important to me in a therapeutic community day centre where I was one of two people who didn't talk in groups. It was important to me to find somebody who had the same feelings as I did. It was one of those impressive therapeutic community places where you had to talk in groups, that was the thing you had to do. It's always that thing about choice and control, and whether you have to fit into the service, or if the service is going to fit around you, isn't it?

Peer-led peer support

This morning we've talked a lot about peer advocacy and community and I am just thinking about the significance of peer support within communities, and originating from communities, and how many organisations that I've worked with over the years that are interested in peer-led peer support. Mind is one of them, also Together (for mental wellbeing) who

I've done a lot of work with. They've done a great deal of work around peer support and perhaps they don't sing their own praises enough.

Peer support and self-help spaces are significant. I think one of the important things for me about recognising what that importance is lies in our understanding of language as well, because we haven't always called this thing peer support. Sometimes it's called service-user groups, campaigning, activism, self-help. It's not always called peer support necessarily, it hasn't been over the decades, but where I think we have the value is that we share each other's voices, we have safe spaces to share our stories of each other, and we create our own knowledge - and the source of the best knowledge is the people who've lived it.

I think for me that experiential knowledge - that knowledge that comes from our own lived experience - is one of the vital things that comes from peer support, or self-help, or our groups, or living with each other. These experiences are the absolute foundation for that experiential knowledge where we come together and learn from each other. We also create new knowledge because we sort of start to put things together, like the Hearing Voices Network, as an example of how strategies are being put together, and we've learned from some of those knowledge communities.

Therefore, one of the most vital ways we can sustain ourselves is by building communities of resistance - spaces where we know we're not alone. There are lots of organisations such as Mind, Together, NSUN - and the Scottish Recovery Network is another one - that



"It was important to me to find somebody who had the same feelings as I did. It was one of those impressive therapeutic community places where you had to talk in groups, that was the thing you had to do. It's always that thing about choice and control, and whether you have to fit into the service, or if the service is going to fit around you, isn't it?"
Alison Faulkner

Guest Speaker - Alison Faulkner



Alison Faulkner

► have done a lot around peer support. A lot of people have been coming up with lots of different kinds of principles and values of peer support, and I guess there are some pretty strong common themes running across. but you only have to blink and somebody else has come up with a list of principles or values of peer support.

Core values of peer support have been put together by Mind for their Side-by-Side programme, the evaluation that was carried out by St. George's and McPin Foundation, based on an evaluation of a whole programme of support for peer support. They are underlined by commonality of experience, safety, choice and control. There are three foundational values, two-way interactions, human connection and then the actualisation of the freedom to be oneself. But in a way you know we can keep doing this forever, keep putting new principles and values around peer support, and I'm getting a bit tired of it, if I'm honest.

I've merged the values of mutuality and reciprocity (which just means the two-way nature of the peer support relationship) but you see how safety and hope, safety in particular, is one of the biggest values. I think that's quite important, as well as hope and empowerment, but safety is really quite a big value, and I didn't necessarily predict that, but I should have done, and trust.

Community-based peer support or peer support as an intervention?

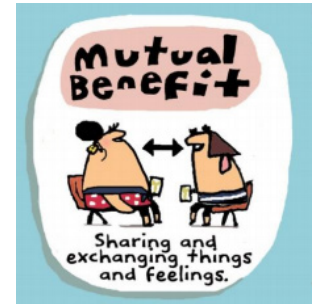
Over the last couple of decades what's happened has been a bit of a divided path around peer support and peer support incorporated into services as an intervention. Some of us are still holding

onto the real value of community-based peer support and I really can't bear thinking of peer support as an intervention.

I have got involved in a piece of research where they are evaluating, using a randomised controlled trial (RCT), which is a widely recognised conventional method of doing research, to see whether peer support, or a particular form of peer support, works or not. I find it so hard to think of peer support as an intervention, but in order to get money to support its use, you have to do something like RCT research in order for it to be validated as something worthwhile funding. That has been a bit of a dividing path for peer support in recent years.

On one side, peer support is an intervention and on the other side peer support is considered as a shared experience. Within services where peer support is seen as an intervention quite often there isn't an attachment or commitment or real values base for peer support. This is a cartoon by Dolly Sen and I'm very happy to feature her cartoons and so this is what it means to be a peer working in services sometimes. Forgive me because I know and I'm sure many people are valuing that kind of peer support as well, I don't want to dismiss that in any way but it does feel sometimes as if somebody has said "this is what peer support is and now you've got to start doing that" and there's a very good paper by Jijian Voronka "Turning mad knowledge into effective labour" and very much somebody this morning said more or less exactly that. So here's some adverts for peer support workers: See Dolly Sen cartoon, page 27.

Jijian Voronka described peer support ►



"I've merged the values of mutuality and reciprocity (which just means the two-way nature of the peer support relationship) but you see how safety and hope, safety in particular, is one of the biggest values. I think that's quite important, as well as hope and empowerment, but safety is really quite a big value, and I didn't necessarily predict that..."

Alison Faulkner

Guest Speaker - Alison Faulkner



Alison Faulkner

- ▶ as: "Turning mad knowledge into effective labour." Here are some adverts for peer support workers:

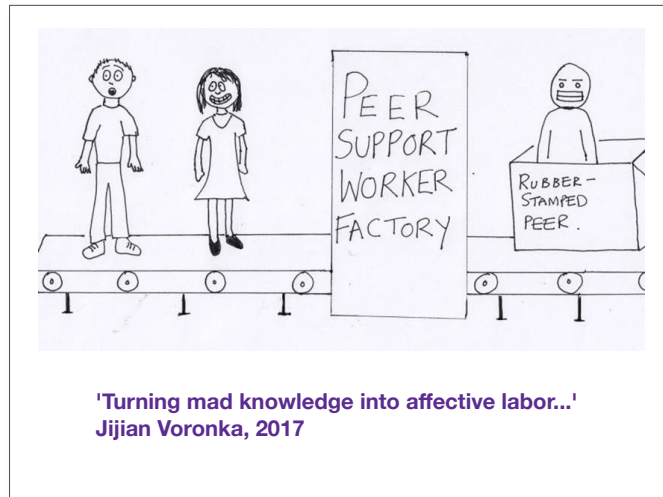
"You'll need a good understanding of the recovery and personalisation agenda and the principles and practice on which mental health services are run. You will show empathy, share experiences, inspire hope, promote recovery with the emphasis in supporting service users on both a group and one-to-one basis to enable them to gain maximum levels of independence in their community"

Not much then!

"Essential qualifications: lived experience, peer support work (of course) and care certificate or completion of care certificate within the first 12 weeks of your start date or NVQ or diploma level 2/3 in health and social care or other recognised programme of learning."

So you've got to actually pass a qualification to do peer support? Somebody this morning mentioned getting involved in control and restraint, which means that we as peer supporters could become involved in things that mental health services believe are necessary, but we as people with lived experience don't. Is that really what peer support is about? I don't think so.

There are another few challenges facing us in the future in this time of austerity. We obviously know there are cuts to services, loss of groups as mentioned this morning, particularly groups in marginalised communities, with BME communities losing groups probably more quickly than white groups. There is also welfare reform and poverty resulting from some of the changes to our welfare benefits.



We're in a competitive funding environment so many of us find ourselves competing with each other when we might want to be working together. That's really hard as well and it applies to voluntary sector organisations and user groups - it's a very big problem at the moment. The individualised treatment model tends to prioritise that one-to-one kind of peer support over more of a group-based peer support and empowerment version of peer support.

I'm not a great group joiner but nevertheless I believe that we find our strength through these routes and some of it is now on social media. I get a huge amount of connection with really important people, some of them are now in the room, on Twitter. Now I know that some people also, including me, find Twitter extremely difficult at times, but there are some great people in our Twitter community that are providing support in a social media context.

Can we find ways of merging those dividing paths? Can we as a mature peer support community start to think in a more sophisticated way about our intersectional experiences, backgrounds and needs around peer support? I think that part of the future is recognising that we're not all the same and we have

Slide from Alison's presentation showing the Dolly Sen cartoon.

Guest Speaker - Alison Faulkner



Alison Faulkner

- ▶ different understandings of what is a peer, and different understandings at different times as well. Sometimes it might be more important to me that I'm gay, and I want to find a lesbian community to connect with, because that actually is really important to me. When I was younger that was really important to me but now it's more important that I connect with the mad community because that's become more a part of my adult life and experience.

Sometimes it's really hard to merge those things and I think we really have to look at the political things going on at the moment, including racism and transphobia, which has been a very big theme in recent weeks and months because of a particular legal reform that's been banned at the moment. I think to be mature our peer support communities need to be diverse and really include everyone. We need to think about whether we are including everyone, and how we are going to do that. I think we need to be more sophisticated about inclusion.

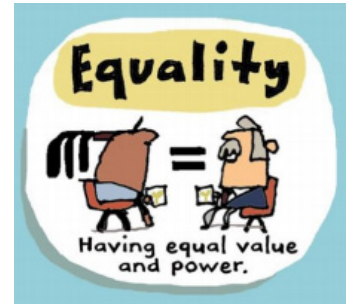
And there's a project I'm involved with called Eureka which is a service-user and survivor-led research programme at the Institute of Psychiatry being led by Diana Rose, and including Jayasree, who will be speaking next. Learning and understanding that people have different ways of doing peer support self-help has come from a lot of different origins, backgrounds and needs. One of the exciting things is learning how some of our compatriots, for example, the users and survivors of psychiatry Kenya group, are doing peer support around rights. They are looking at peer support much more as empowerment and decision making around people's citizenship

and rights, as you can see from a really interesting report on their website. This is a quote from that report: "The individual then goes out into the world with a different outlook as an empowered agent rather than an object of treatment." That applies very much to how we would like to think of peer support here too.

This connects with the complicated concept of epistemic injustice, which essentially is about not being believed. This is from an activist in the States who says that a lot of what we do in peer support and in our communities is great but does it address the core, root cause of our question? The root cause is seen as the societal belief that people with psychiatric diagnoses or mental health challenges are not credible reporters or witnesses of their own experiences. In other words, when we speak we are not believed. I think that is just such a powerful way of thinking about the future of peer support - can we reignite the sense that we actually are credible witnesses of our own experience?

One final quotation, referring back to Sherry Mead:

"As peer support in mental health proliferates, we must be mindful of our intention which was social change. It's not about developing more effective services but rather about creating dialogues that have influence on all of our understandings, conversations and relationships." ●



lisaholdcroft.com

"One of the exciting things is learning how some of our compatriots, for example, the users and survivors of psychiatry Kenya group, are doing peer support around rights. They are looking at peer support much more as empowerment and decision making around people's citizenship and rights, as you can see from a really interesting report on their website."
www.uspkenya.org/

Guest Speaker - Jayasree Kalathil



Jayasree Kalathil

► **D**ominic Makuvachuma can't be here today so I'm going to talk about the project that I'm involved in with him. I've talked a lot about peer support before and you can find that on the internet. The project has an asset outcome, what used to be peer support, and what I like to still think of as self-help.

When NSUN started in 2007, it shared an office in Vauxhall, London, with the Afiya Trust, which used to be the National London Minority Ethnic User Survivor Network called Catch Afiya. Catch Afiya died because the race equality agenda went off the programme and the funding went with it. The Afiya Trust also died in 2012 because there was no more funding for race relations work.

One of the first pieces of work that I was involved in with NSUN and Catch Afiya was about the user involvement of people from black and ethnic minority communities. It was called: "Dancing to Our Own Tunes". One of the recommendations from that was to create a network which would connect people from racialised groups to work together collectively, support each other, and to share information.

We did a review of how the report's recommendations were going in 2011. By then Catch Afiya was dying. Then in 2013, we put together a proposal to look at what actual work there was around the country by people from BME communities who are user survivors, as by then austerity was in place and a lot of the organisations weren't there anymore.

Reigniting the Space project

It took about four years for anybody to

get interested in this work but eventually we got there. We got some funding from the LankellyChase Foundation and so we are 'Reigniting the Space' (project name) for BME user survivor activists and networking. We have been recruiting members to the steering group from all regions in England and some of them are in the room today. There is Mustak Mirza representing West Midlands, Hameed Khan representing the North West, Sonia Thompson representing the East Midlands. We also have representatives from London, Colin King; also from the North West, Hanif Bobat; June Sadd from the South West; Satwinder Kaur and Libet Brown from the South East. We have still to recruit for Yorkshire and Humber, and we also don't have a representative from the North East, so people from the North East, please do suggest and ask your colleagues to approach us.

The first stage in this project is to see what's going on in the country. As already said, most of our work has disappeared, and for me this is interesting because I'm also currently involved in writing the history of black survivor activism. I'm going around the country interviewing user survivor activists right back from the 70s onwards. Perhaps you didn't know that there were black mental health service user survivor activists in the 1970s because you didn't see them. There are, however, and there have been groups who've been doing work. What we don't have is a potted history as our work doesn't really get recorded, and our history doesn't really get told. For me it's kind of slightly poignant because on the one hand I'm looking back to what our history has been but on the other we're ►

"We have still to recruit for Yorkshire and Humber, and we also don't have a representative from the North East, so people from the North East, please do suggest and ask your colleagues to approach us."

Jayasree Kalathil

Guest Speaker - Jayasree Kalathil



Jayasree Kalathil

- ▶ launching this new network, in some ways to do again the kind of work that people used to do in the past.

I was in Manchester yesterday interviewing somebody who's been active in the region since the early 80s. He was talking about the self-help that he used to do for the South Asian community in Manchester, service users going into wards, and just sitting and talking to people in wards - just companionship, relationship building, just being there. Now this has become quite an accepted form of peer support work. The point I'm trying to make is that it's not like it wasn't happening, and it continues to happen, but it gets very

institutionalised in many ways.

We will start by mapping what work is currently being done around the country led by user survivors from BME communities. We'll be doing two pilot sites, one of which is the East Midlands, which is an interesting place to look at the diversity of history of the communities who live there. The other site is going to be London. We will look at what's happening now, who's doing what and then take it from there in terms of rebuilding, Reigniting the Space for BME activists within mental health. ●

"I was in Manchester yesterday interviewing somebody who's been active in the region since the early 80s. He was talking about the self-help that he used to do for the South Asian community in Manchester, service users going into wards, and just sitting and talking to people in wards - just companionship, relationship building, just being there."

Jayasree Kalathil

Guest Speaker - Mark Brown



Mark Brown

I've been thinking a lot about what it means to work together and to support each other. I recently gave a lecture on the question of where hope comes from and what we need to keep it alive. This is like a bit of a 'too long; didn't read' version of that.

My main thought is how can we even think of lecturing the rest of the world about how they should treat us if we cannot even manage to look out for each other?

There is no peer work without the presence of pain and loss and grief and anger and sadness. We cannot undo our own pasts and our own disappointments and terrors by doing good work for others. We all begin our experiences of mental distress alone and confused and forsaken. When we have been through those things and found ways to grow and learn and be ourselves, then we can also extend a hand of welcome and support to others who need somewhere safe to be until they can find their own answers and their own paths.

If we are dealing with the inhumanity of a benefits system that has actively discriminated against us, a medical system that still hasn't caught up with what we need and want and a wider society that talks a good fight about caring about us but often does the opposite of what it says, then what we say and do to and for each other matters.

Collective action means collective power

Patrisse Cullors, one of the founders of Black Lives Matter, early on described the movement's mission as to:

"Provide hope and inspiration for collective action to build collective power

to achieve collective transformation, rooted in grief and rage but pointed towards vision and dreams."

Changing the world is as much about finding ways of living together with what hurts us and being able to be authentic and vulnerable and powerful with each other, as it is about fighting and shouting and politicking. If we can't be with each other and help each other and comfort and challenge each other between the fights and the horrible stuff we're building a movement where there are loads of political posters but no love and no hope.

Finding other people who have lived through similar things to us can be like finding a family that you never knew you had. But sometimes, not all the time, what we at first feel will be a new home for us and the family we never had ends up more like the family we did have that didn't help and leaves us feeling doubly rejected and doubly shunned. There is a special kind of aloneness when we find even our own people couldn't manage to stop fighting and letting us down.

Tea and biscuits across the world?

If we do have a network and we do have a movement I'd love to think that it was friendly faces with massive cups of tea and loads of biscuits spread across the country, or even the world, that could be a place of warmth and nourishment for us wherever we find ourselves. Imagine that wherever you are, wherever you were visiting, you knew that you could get in touch with a local group of people who've experienced distress and say: "I'm in town: fancy a cuppa?" Imagine knowing that if you needed to, or wanted to, there were places to go where you could just ►

"If we are dealing with the inhumanity of a benefits system that has actively discriminated against us, a medical system that still hasn't caught up with what we need and want and a wider society that talks a good fight about caring about us but often does the opposite of what it says, then what we say and do to and for each other matters."

Mark Brown

Guest Speaker - Mark Brown



Mark Brown

- find your people. People who get it. Not as a service, not as a contract or a part of services, but just a kind of fellowship of friends you've not met yet.

When we come together to make and do things together as people who have lived with, and live through distress, we make ourselves vulnerable. Being vulnerable is not the same as feeling safe. When we cannot feel safe and valued we cannot help others to feel safe and loved and find ways of showing that things can sometimes be good and fun and warm when everything else is dark and cold and awful.

If we are building our movement we will do it on making spaces that buzz and crackle with energy and anger but which also nurture and make us safe. In a world where so few of us have found family and home and community, this must be part of our home.

The problem is we don't always know how to be in each other's houses. We've sometimes been so used to fighting that we forget how to extend a hand to someone and tell them they're welcome and it's OK just to hang out for a bit. Terrible times can have an effect that gets into your bones, makes you unable to stop fighting even when the job in hand is to relax and feel safe. Sometimes I'm scared that we forget how to say: "Come in, do you fancy a cuppa" and so end up meeting people and just shouting 'THIS IS SPARTA' and looking for someone to kick.

Saying yes to hope

We can spend our lives fighting the world, becoming a massive world shaking, throat scorching shout of NO, but to build

a movement we need to also learn the art and vulnerability of saying yes. We get boxed into thinking all we can do is make a noise about what we don't want. But we have to find ways of working out what we do want and making it happen.

Hope comes from seeing things in action and action comes from the hope that the future can be different. Rebecca Solnit in her book 'Hope in the Dark' talks about where hope comes from and how hope is the vital element of change. For Solnit, hope comes from jumping in and doing stuff. She writes:

"Hope locates itself in the premises that we don't know what will happen and that in the spaciousness of uncertainty is room to act. When you recognise uncertainty, you recognise that you may be able to influence the outcomes—you alone or you in concert with a few dozen or several million others. Hope is an embrace of the unknown and the unknowable, an alternative to the certainty of both optimists and pessimists. Optimists think it will all be fine without our involvement; pessimists take the opposite position; both excuse themselves from acting. It's the belief that what we do matters even though how and when it may matter, who and what it may impact, are not things we can know beforehand."

Together we have to build spaces and places and relationships where we can keep hope alive. We do that by making spaces that have a place for the terrible things that have happened and also for the even more terrible and risky business of actually doing things to make the future better. Solnit says that we can't begin to picture a future without admitting and exploring our history. She says: ►

"Hope comes from seeing things in action and action comes from the hope that the future can be different. Rebecca Solnit in her book 'Hope in the Dark' talks about where hope comes from and how hope is the vital element of change."
Mark Brown

Guest Speaker - Mark Brown



Mark Brown

- *"A memory commensurate to the complexity of the past and the whole cast of participants, a memory that includes our power, produces that forward-directed energy called hope. Amnesia leads to despair in many ways. The status quo would like you to believe it is immutable, inevitable, and invulnerable, and lack of memory of a dynamically changing world reinforces this view. In other words, when you don't know how much things have changed, you don't see that they are changing or that they can change."*

The only people who can tell a true history of the last ten years of austerity and how it has affected people who live with mental distress is us, all of us. It won't be the same story for everyone and nor should it be. We all live with different discriminations, different power imbalances, different challenges. But collectively it's only us that can tell that story. And it's not the same story for everyone.

If we are committed to peer work around mental health and mental distress the thing we know for certain is that our peers are going to have gone through some shit and will probably go through some shit again. Yet again and again we create situations that do not reflect that reality, as if somehow we might magically find the right recipe and never have to think about the ways that our experiences have pushed us out of shape and made us cranky and touchy and vulnerable. I'm not always the friendliest person. Sometimes I shoot my mouth off. But I'm doing by best to never talk over others even when listening is difficult. We know our friends and colleagues are people who go through bad shit; let's make sure we actually build that into the way we treat each other.

There has to be a place for acknowledgement of anger and loss and sadness but also an acknowledgement that anger and loss and sadness changes us, pushes us out of shape and makes us into the people we are. This makes it even more important that we find ways of being safe with each other and building spaces and places and relationships that can help us grow and find ourselves and find each other and find our power.

Being a practical sort, how do we actually make this movement of friends and peers? I like the approach of the folks in the North East: make as much stuff happen as possible; see how it goes; make things friendly and safe. Hope comes from seeing good things happen. A cup of tea and chat might not change the entire world but it can change two people's worlds forever, and then they might go on to change the world for others in turn.

For the first time, there are loads of people talking about mental health and trauma and distress. There are generations below me that are looking for things to do to make peoples' lives better while owning their own distress. They're already thinking in terms of building political and practical movements and they are proud, and they fill me with hope.

If we can't put our values into action with each other for each other, showing how we value each other and find ways for us to live with and through awful things, then what hope do we have of ever convincing anyone else to listen to what we say? What gives me hope? People finding their power does. People making the future that isn't awful does. People not being

"A cup of tea and chat might not change the entire world but it can change two people's worlds forever, and then they might go on to change the world for others in turn."

Mark Brown

Comments from the floor



l. Mark Brown,
m. Alison Faulkner,
r. Liz Maitland

► **Julia Smith:** That was a powerful speech you gave there and very comprehensive and it's a kind of summary of today because it's a lot of the stuff I've been thinking about while other people were talking.

Mark Brown: Well that's always a good feeling when you manage to get it right when you haven't heard what everyone else was saying before.

Floor: Alison, I was wondering what your thoughts were on the big flavour of the NHS at the moment, which is social prescribing, which is meant to link people in with peer community groups.

Alison Faulkner: My feeling is that it's great if there is something there to prescribe for people because if there are no peer support communities locally you can't really prescribe it for somebody. I'm a little confused as to how it really works in practice and as to whether there's funding to make sure there is something there to prescribe.

Mark Brown: Social Prescribing is a really interesting thing in that everyone agrees that it is kind of a good idea up until anyone talks about how social prescribing might happen, or what it's for, or why you do it. Don't confuse the idea of social prescribing with the idea of making things happen in the community. The only reason to get them confused is the idea that the public sector will pay for things in the community.

Liz Maitland: I just want to say something about social prescribing. At Recovery Assistance Dogs, we applied for some funding because our perception of it is that instead of doctors prescribing medication, especially for young people

which is very traumatic for them, that they can prescribe something which is going to help them with their mental health to help them with their confidence, help them in the community. So we applied for this funding and we were getting the funding as long as we could find doctors that would engage with us to take a group of dogs and help a group of young people that the doctors recommend to help them to recover by engaging them with their pets, and training them to train their dogs, cats, rats, bats whatever they had.

The doctors didn't reply at all, I emailed, rang, nothing, not interested at all. So I talked to the funders and they said to go to schools. I used to be a school teacher so that was my baby a bit more and they responded. And we're starting the project, we got the funding, we're going to the schools, we've got to find a school to properly engage, get the posters and leaflets done, and go and engage with the young people in the schools, and train their dogs and help their families, helping them to be a bit more sustainable. So that's what I think social prescribing is about, it's not so much about avoiding the drugs necessarily, it's about helping people to recover so they don't have to access the psychiatric system in the first place. This is the way I'm targeting it.

I'd also like to say, that instead of peer support, we need to be looking at positive discrimination. Positive discrimination is something that's helping you with your disability. So people know you've got a disability, and as soon as I'd completely recovered and I was discharged from the psychiatric system and taken off all the drugs, I felt like I had strength to talk about what I'd been through. I was ►

"I'd also like to say, that instead of peer support, we need to be looking at positive discrimination. Positive discrimination is something that's helping you with your disability. So people know you've got a disability, and as soon as I'd completely recovered and I was discharged from the psychiatric system and taken off all the drugs, I felt like I had strength to talk about what I'd been through."

Liz Maitland

Comments from the floor



Nigel Moyes

- happy to have a dog to show that I had mental health problems. I've already noticed that in the community, people really care about mental health, and put on kid gloves to look after us. Let's move it forward in the 21st century looking for something that helps people recognise what we've been through, and not everyone can have a label or everyone can have a dog, but for people to recognise it and treat us properly.

Nigel Moyes: Very interesting to hear what Mark was saying and I'd like to hear his spin on how we can get the voice of children and young people into the arena. Social media is forever changing, and they know they're different in the way they're brought up. These days, as soon as they come out of the womb, they're on ipads etc and I would like to suggest that we look at some sort of wellness plan, some sort of rights for the people around them to actually have their thoughts put down because, if not, the future for the future generations to me is a scary one.

Mark Brown: You talk about how we've evolved, people younger than me in this world of doing mental health stuff? I think the answer is that people younger than me are already doing mental health stuff. What I think we've often done as older generations who fought different battles is to lecture young people for not knowing the history, and for getting it all wrong, and for not being interested in the same things that we are.

Growing up with a mental health difficulty, growing up with distress now isn't the same as growing up with a mental health difficulty or distress 20 years ago. If we're talking about involving young people in the things we're doing, we have to

be respectful. Often what we're doing is jumping into their spaces; and we're not inviting them into ours. When you go into someone's house, take your shoes off, don't tread mud in. I kind of get this feeling that we'd love to lecture young people about what they're doing wrong, and it's like we're not doing an amazing job of doing stuff right ourselves to be honest.

We've got different parts of the puzzle, if you like, and I think we can have incredibly important and useful discussions about why we are moving in the same direction. The widespread 3G reception that made mobile internet possible arrived in the UK about the same year as austerity did. I think we often confuse the effects of austerity and growing up under 10 years of huge amounts of cutbacks in the public sector and opportunities with the effects of having a smartphone. It's like I think young people now can say: "We've got the internet, and we've got smartphones and access to porn any time we want it, but what we had to give up for that is libraries and educational opportunities, advancement, work and the thought of ever having your own home." Whether that's a good trade off or not, young people didn't get the choice of whether to make it. ●

"Growing up with a mental health difficulty, growing up with distress now isn't the same as growing up with a mental health difficulty or distress 20 years ago. If we're talking about involving young people in the things we're doing, we have to be respectful. Often what we're doing is jumping into their spaces; and we're not inviting them into ours."

Mark Brown

Table Discussion



Introduction

Sarah Yiannnollou

We talked in the break about ways to help people connect with others they wouldn't necessarily get the chance to talk to - if you have any ideas about that they would be most welcome. For the last part of the day we wanted to have a reflection on what people have heard and start thinking about what next? What do we need to do? What can we do together? What is possible when we use our collective knowledge, experience and strengths?

Please take five to ten minutes on your tables just talking to each other, catching up. Write your ideas on these little speech bubbles and then we can pull out some of the key ideas and thoughts in a group discussion. Hopefully we can start thinking about how they influence our next steps - and also not just our next steps as an organisation, and the work that we do with Mind and others, and all the partnerships that we've made through developing the peer support charter - but also the wider, bigger picture for peer support as well.

I just want to remind people about the members' manifesto - we will be refreshing it. We always reflect back following these meetings. On the table are copies of the charter and we've also got a questionnaire that asks for feedback on the manifesto points. There's also an online version but I'd really like to ask people to take a bit of time to do that for us.

Just before the table discussions, I want to make a couple of points. One, I think today - just the feel of today, the contributions that people have made,

the support people have given each other as well - truly represents what peer support or mutual support is all about. As Jayasree said, 'self-help', and the mutual support in the room has been fantastic, so thanks for that. We need to acknowledge that not everybody's views and positions around peer support are necessarily able to be represented in one day.

I just had a conversation with someone talking about peer support workers who are employed in Trusts who we've worked with on the Peer Support Charter - their voices are really important as well. There's lots of issues around people's status and equality. That includes some of the issues that they're facing individually but also as members of a team. Some people are in a really difficult place of possibly not being seen as part of the survivor community, but not being seen as part of the professional community either. There's lots of issues to think about in terms of whose voices we are including and what issues we need to be looking at. ►

DISCUSSION QUESTIONS:

- What are the highlights of peer support work to date?
- Where is innovation occurring? What does it look and feel like?
- What do you think the future of peer support looks like?
- What do we want to see happen in five years' time?
- What are our national priorities?
- What challenges do we face and how are we overcoming them?

Table discussions



► ● TABLE 1

Hameed Khan

We were looking at the first question "What do you think are the highlights of peer support work?" I want to bring another perspective into this. In Australia, they have been fantastic in pioneering where peers run mental health services for peers, and professionals only get involved where peers feel specialist services are required, for example, a psychiatrist, a nurse or a social worker. I would love to see us also move in that direction in the future.

Let's not forget that we are very innovative, and we should be very proud that we have the annual Peerfest, where we get to celebrate that we make this happen. We also support people throughout the year, which doesn't cost the government much money as most peer support groups run on peanuts.

Finally a point was raised about impartiality, that the reality is it's sometimes difficult to be impartial, especially when you're passionate about something or affected by something. However, we really want to create, and not shy away from, free thought spaces. That basically means that people can say, and feel, and express what they want and see the future of peer support work. Let's try to create that, and not shy away, because I think shying away and trying to be too politically correct is killing and dampening our creativity. It's a space for creating innovation.

Speaker 2

We talked about the fact that we're always speaking to people of a like mind. We wanted to try to open up opportunities for people with whom we might disagree in order to engage them in the conversation.

This is primarily because they have a lot more power than us. I talked very briefly about a process of co-production and innovation called the AU process. It creates opportunities for opening up dialogue because it's very easy to do a lot of downloading in terms of listening to one another. We listen, and we tick the box, because that person said exactly what we already believe. There are different levels of listening, and we want to open up spaces for generative conversations.

There are some people who might be considered to be on the opposite side to us who might want to come in and take this journey with us. This would help us to move towards a type of innovation where we get more resources, and we don't keep creating solutions that are exactly the same as the ones that have been going on for a long time.

This process includes all of us thinking about what it is that we might need to let go of, something that's getting in the way of us moving forward, prototyping the new future not just piloting it. One of the problems of piloting is that a lot of resources go into creating this new project, then it gets tinkered around with. Alternatively there's lots of learning that can keep happening if you let go of the idea that you have to produce something that is completely right, if you are prepared to learn from mistakes, as opposed to blaming people when things go wrong. Finally, when you have created this new future, you try to embed it within your organisations.

● TABLE 2

Speaker 1

We talked about quite a few different

"Let's not forget that we are very innovative, and we should be very proud that we have the annual Peerfest, where we get to celebrate that we make this happen. We also support people throughout the year, which doesn't cost the government much money as most peer support groups run on peanuts."

Hameed Khan

Table discussions



- things. To start off with we said some of the key things from today that have been really important for us to take away are around authenticity. It's about how important authentic connections are, and being real, especially within the climate of everything being professionalised, and being made into a package, with performance indicators. There's something really important about keeping that organic authenticity and not having an agenda and having a space to have that organic authenticity.

Another important thing for me was around trust and safety and that came up when Alison spoke. Hearing conversations - I think it's something all of us have experienced when we're feeling at our most vulnerable. People letting us down - and then it takes time for us to then trust and feel safe. We need that time, and we need that space, and how important it is to have this space here that feels very safe and feels very authentic.

The third point was the importance of sharing information to empower us. There's lots of knowledge in this room. There's lots of skills and it's about how we make best use of those skills and knowledge, so that we can empower each other. That is something that NSUN can enable us to do because everything I've heard today has been inspired and invigorated me.

Mustak Mirza

Alison Faulkner talked about peer support as an intervention. Every Trust is now bringing peer support workers into the NHS. To me, if you work in a hospital surrounding, and you are supporting patients or service users, the question is are you a peer? Are you doing the right thing?

Speaker 3

Just to say thank you so much for putting on today and can we have more events like this and at a regional level.

● TABLE 3

Julia Smith

People in the NHS are trying to take over peer support and it's our last bastion, it's the last thing that we have ownership of. We can't just let it go to other people, we need to fight that. They might think they're doing peer support, but we can tell them they're not doing it the right way, and we can show them how to do it the right way.

About the question: "What challenges are we facing?" We need to get the balance right between technology and reality. Most young people these days rely on technology and social media at the expense of reality. We need to keep their feet on the ground, we need to make sure they are including a bit of reality.

● TABLE 4

Speaker 1

We echo some of the challenges just mentioned, like when peer support's being owned by Trusts and doing risk assessments. It's taking away from what peer support is meant to be and we need to take it back. We said ideally in the future we'd like services only to be provided by professionals and lay people with lived experience and no tokenism, no more professionals taking their token service users along to get their funding, it would be the other way around.

Ben Glass

We went a bit off piste from what

"What challenges are we facing?" We need to get the balance right between technology and reality. Most young people these days rely on technology and social media at the expense of reality. We need to keep their feet on the ground, we need to make sure they are including a bit of reality."

Julia Smith

Table discussions



- ▶ you wanted us to do. One of the challenges that we identified was that the government is literally killing us and getting away with it.

Challenges with the culture of peer support and peer support as an intervention - we kind of took our cue from Malcolm X, and said we want to stop singing and start swinging. We had a conversation about the history of the user movement, and about direct action, and not talking but getting things done. We thought that is what we need to do although there are service user survivors who understandably are afraid of taking these kind of risks. They are concerned about the effect on their benefits, their status with the mental health services, and all of that. While we have complete respect for their views, there are also patients and service users who are prepared to take those risks.

We therefore want to form a network of militant mad people who are prepared to take the risks, get into trouble, and cause a lot of trouble, and we want to start forming that network today. We want to undertake direct actions which challenge and test the legal and moral frameworks that we are expected to live by. We want to take action to ensure meetings/conferences about mental health have survivor/ service user speakers to discuss the issues that we want them to.

We have 'Nothing about us without us' as a mission statement but look at any mental health conference or meeting - professionals just talk about what they want to talk about.

We need to get some legal advice and support for ideas about direct action. Service users are beginning to record

their appointments, which is entirely legal, but professionals don't like it. Service users need some coordination, national action on that. We need to put up posters and stickers about what's going on, what our demands are, in wards, Community Mental Health Teams and council buildings. We need to expand and strengthen the survivor/user media, to find those stories, knowledge and skills. There's lots of survivor media out there but we can definitely widen that.

We want to get a national network of patient councils. We want mental health services to be run based on the democratic demands of patients themselves. We want to find those professionals and allies who genuinely have solidarity with us and form revolutionary unions between professionals and patients. We'll have a revolution by teatime tomorrow...

Speaker from the floor

The Mental Health Resistance Network is already in existence, it's already being done. I personally wouldn't get involved with them as I don't like their beliefs, but they are there if you want to get involved with them.

● TABLE 5

Nash Momori

We were looking at the highlights of peer support to date and we had a very interesting conversation where we used two case studies. These were about people who had been admitted to a psychiatric hospital, or taken to prison, and felt when they first arrived as if their whole life had been shattered. Staff ask you: "How are you feeling?" You say you are stressed and scared, and they reply: ▶

"Challenges with the culture of peer support and peer support as an intervention - we kind of took our cue from Malcolm X, and said we want to stop singing and start swinging. We had a conversation about the history of the user movement, and about direct action, and not talking but getting things done."

Ben Glass

Table discussions



- ▶ "Never mind, we have a peer support worker coming in by tomorrow." It just feels like for years we've been providing that kind of support to each other, and to us it feels like peer support is losing its authenticity.

Lastly, we looked at the question: "What will peer support look like in five years' time?" At the moment we're in an e-world and there are e-communities everywhere. I've seen couples at home, wife in the kitchen, husband in the bedroom and they are communicating through text. How can we best support each other without necessarily being able to see each other, because I know I go through certain challenges in London, and I identify with someone doing the same in Manchester. Does it mean I have to travel there though? Or can we create a platform that can supply that support when we need it?

Joe Kelly

I think NSUN needs a bigger public persona, a lot of people don't know NSUN unfortunately; you need to be more visible. Me and some of my friends participated in Notting Hill Carnival and we were visible. Michelle Baharier does some amazing work, for example, various different walks. When you're more visible you are entering people's minds, and you're more visible when you have something to say.

● TABLE 6

Speaker 1

We have a few slogans at our table. One is: "One servant, two masters." We were just thinking about people who are employed in the NHS as peer support workers because they need to pay their mortgage but they also want to be a real peer supporter too. In the same way we were looking at volunteers versus

support workers. We also mentioned changing the mindset of mental health professionals so that they are of more service to the service users.

● TABLE 7

Speaker 1

We started having an interesting conversation about this idea that the NHS and other bodies may be taking peer support and - in many eyes - destroying it, changing it, manipulating it. That begs the question: "Why is it going so wrong," when we in this room feel so passionate about it, when there is so much expertise and knowledge. Why is it going so wrong in some of these organisations? Why aren't we able to effectively influence at a greater level? Do we have a seat at the right table? Are our voices respected when we do speak up?

I'd love to say that we devised the art of that in some sort of five-point plan, but we didn't, sorry to disappoint. However, it did lead us on to thinking maybe we don't have a lot of the energy that could be created from things like today. Nationally our influence could grow, but a lot of the time we're kind of all doing our own things in small areas, and we don't really get a chance to share that on a greater level.

We spoke a little bit about culture changes, and I think that's really unfathomable, at least it is for me. It's not very tangible when we talk about culture changes. We spoke about a few instances in the NHS or other settings where we acknowledge how peer support is being used in a way that they think is correct, and that they think is valuable. That's within their culture, and ours is very different - not to say that we need to dictate to them. We were all ▶

"How can we best support each other without necessarily being able to see each other, because I know I go through certain challenges in London, and I identify with someone doing the same in Manchester. Does it mean I have to travel there though? Or can we create a platform that can supply that support when we need it?"

Nash Momori.

Table discussions



- ▶ saying about how we shouldn't dictate peer support, it should be organic, but we often say how we should dictate it to the NHS and others. That is a bit of a conflict of the views and beliefs that we have, so it's kind of trying to start to work with, rather than work against, to try and enable peer support to be available and effective at all levels.

● TABLE 8

Rachel Rowan Olive

We talked about how people are caught in situations where they want to hold all the failings of a broken system and try and fix them themselves, and the need to come together and validate how difficult that is as a starting point. Whether that's feasible I don't know.

A lot of the time it's a really frustrating place to be. I feel personally that I'm going to burn out a lot of the time. Someone who has really supported me in my involvement works says I've been doing this for a long time. Times are really hard, and there's things that we've held on to, and we feel like we're just pushing against the tide all the time. We're just spending our lives pointing out obvious things - but maybe there are things that we've managed to keep going that wouldn't still be here if we weren't pushing all the time. I'm not sure whether I fully believe that at the moment, but I wanted to put it into the room as a hopeful note at the end of the day.

May be even if it feels like a lot of things are just very hard not going backwards - or at least not going as far backwards as we otherwise would have done - that is progress in itself.

● TABLE 9

Speaker 1

I want to talk about: "What does peer support look like in five years' time?" I'm really hoping that there's some sort of code of professional conduct for professional peer support workers which excludes things like restraint and seclusion work. The other thing that I thought was a highlight of Alison Faulkner's talk was this thing about doing a position description for a peer worker, and the different range of training.

In Australia they have dedicated courses for mental health peer workers where they have to have a college qualification that is called Mental Health Work for Peer Workers. In the US people are struggling with the certification process. There are a number of training programmes that are well established, for example, Intentional Peer Support developed by Sherry Mead in Massachusetts. Mary O'Hagan has developed peer zone work in Auckland. I don't see any evidence of any of that being developed or implemented in this country, which is a clear gap that I hope people will make an effort to fill. This would provide a really strong basis for this kind of practice which would eliminate the moral and institutional barriers to people practicing as peer workers.

Speaker 2

Sometimes when I come to these meetings you see some things as very negative. There's something about statutory services using peer support work which has its good points - it's how we interact, and what we can do to bring out these good points. It is very subjective how things work for some people and not for others. ▶

"We're just spending our lives pointing out obvious things - but maybe there are things that we've managed to keep going that wouldn't still be here if we weren't pushing all the time. I'm not sure whether I fully believe that at the moment, but I wanted to put it into the room as a hopeful note at the end of the day."

Rachel Rowan Olive

Table discussions



► ● TABLE 10

Speaker 1

I'm very glad that things are being said about peer support workers within the NHS. I've found myself sitting here among people who are peer support workers within the NHS and they're lovely people, and they took their jobs in good faith, and please don't attack them. Having said that I just walked away from an NHS job because I didn't like the way they were implementing peer support.

How do we get peer support working in the NHS when I know from my many years of working and of a lived experience role within it, that it cannot even defend the professional values of nurses, occupational therapists and doctors. I can only think of one way to do this: we need to keep fighting, we need to keep our ideas on the agenda and we need to try and get ourselves more of a voice.

Speaker 2

What we looked at was not just whether peer support is a good thing but what it is that people get out of it. I reflect back on 20 odd years of being in and around services, and for me peer support works when you get a sense of acceptance, when you get the sense of being understood, when you get the sense of somebody standing alongside you while you're in distress. Why the hell can't the NHS deliver that? For me, that's basic care.

The problem that I have a little bit with peer support being viewed as exclusively the domain of service receiver groups is by definition it's exclusionary. When most people experience distress they go to the NHS, they don't go to the amazing groups

that are dotted around that we've heard about today. So for the good bits of peer support to be felt by most people, is the NHS the means to deliver it?

Not every Trust of the NHS is capable. Certainly the Trust I work for is incapable of doing that. What I would like to see is rather more conversations about how to change the culture of our NHS organisations. We need to think about how we shift the focus so the benefits of peer support can be felt by most people, instead of focusing on the fact that we've got a really good thing we need to keep pure, and that we don't want to let the professionals anywhere near it.

Speaker 3

There's been a lot of talk of co-opting. I'm an NHS peer worker and it's going to be co-opted and walking away is not helping that, I feel. I know what I and people I know do with people is really important. A lot of the people that we see talk about never having met anyone who's had a similar background or experiences to them. For whatever reason they haven't been accessing these really great groups or things that are happening in the community. They'd be left out otherwise, and I don't want the things you're talking about to happen.

I came here wanting to connect with people and to actually feel like I'm part of a community of people who believe in peer support and have found each other. I wanted to discuss the spectrum of ways it can happen, and be meaningful to people, but instead I feel a bit like should I be doing my job? Should I leave? But I don't want to do that, I want to stick up for the good things and the importance of them. I want to do that with every-

"I reflect back on 20 odd years of being in and around services, and for me peer support works when you get a sense of acceptance, when you get the sense of being understood, when you get the sense of somebody standing alongside you while you're in distress. Why the hell can't the NHS deliver that? For me, that's basic care."

Speaker 2, Table 10

Table discussions



- ▶ body. That's how I feel, and I'm open to anybody talking to me about it, even if they're different - I accept that. Just let's try and make something available for people, in whatever way.

● TABLE 11

Paul Radin

Listening to what people are saying, I'm just wondering if we're really learning the lessons of the past. It seems like we're in this cycle of creating something, then it gets nicked and corrupted, and we moan about it forever. Then it happens again and again, and that's a problem we have to solve. I just wonder if we can create something that isn't nickable, and I think the secret is to take the money out of it. If we de-professionalise things, and bring peer support back to just people helping each other out for mutual benefit, with no exchange of money, no power differentials, just people meeting up for a coffee and helping each other, if there's no money in it no one will want to nick it off us and it will stay ours.

Alisdair Cameron

We also started talking about how there is no formula. One of the elements I think we all encounter, whether it's in statutory services or the voluntary sector, is that there's an expectation for things to be scalable or for uniformity. I think we need to push back against that, whether it's peer support, in a Trust, NHS England or the voluntary sector. There isn't a template, there isn't a set way of doing things, it's often by happen stance or serendipity that you get a certain number of people who've got lived experience coming together.

Let's not go for uniformity, or a formula, but accept that there will be many

different varieties of what goes on. In some ways the term peer support has become a red herring. Everyone expects it to be this big tent under which a lot of things fit. Let's strip that away and look back and ask: "Are you doing good things?" If you're doing good things with other people who have lived experience, then let's celebrate that, and forget about what it's called, and the pressures to scale it up, or to have a rule book, because there are no rules.

Speaker 3

I have wanted to form a union for survivors for a long time, I wanted to call it 'Survivors that Have Infiltrated The System,' or 'SHITS' for short. If anyone wants to help me start that union please get in touch!

Debbie Roberts

If we're talking about "it's going to be done anyway" – then why not be part of the solution? The amount of experience and ability in the room is huge – so why not be their consultants, their advisors, their collaborators? Try and help them do the best they can. There are some brilliant people in here who are saying they already do it, and good luck to them, and keep working on that.

The second point is Apple, the computer company, and I know not everyone likes them but why are Apple so successful? Because they keep moving forward and they keep doing their own thing. They don't keep looking back and copying what others are doing or wonder who's copying them. Don't worry about what others are doing, just eat your own apple.



"It seems like we're in this cycle of creating something, then it gets nicked and corrupted, and we moan about it forever. Then it happens again and again, and that's a problem we have to solve. I just wonder if we can create something that isn't nickable, and I think the secret is to take the money out of it. If we de-professionalise things, and bring peer support back to just people helping each other out for mutual benefit, with no exchange of money, no power differentials, just people meeting up for a coffee and helping each other..."

Paul Radin

Closing comments



Sarah Yiannoullou

► Sarah Yiannoullou

Sarah thanked everyone for their contributions, the lively debate and the sharing of experiences and knowledge. She said that the passion and solidarity is what makes these events so special and inspiring, as well as how we acknowledge and hold our differences in a safe space. The network is about supporting our ambitions, as individuals and groups.

Main points of the discussions include:

Be careful what you wish for:

Lobbying and campaigning for our ways of working and thinking to be recognised and adopted, then when they are, saying we don't recognise them – "that's not what we meant." **We will continue to challenge these misinterpretations and representations.**

Survival of user-led groups:

Fighting for survival when other organisations are moving into the spaces that user-led groups have created and inhabited. **We will campaign to raise the importance of user-led groups and the challenges they're facing.**

Listening to and acting on what our members tell us:

It's not just about producing charters and standards, it's what we do that demonstrates our principles and priorities. **We will review the Members' Manifesto and plan all of our work based on members' priorities.**

Moving forward:

Learning from the past and not just saying what we don't want but being able to collectively say: "This is what we want and this is when we want it, moving forward more confidently and being able to communicate our uniqueness as a collective." **We will make our position known and include more people in our policy work.**

Sarah spoke about the struggles that many groups are facing and reflected on the call from some to be more militant, bigger and bolder. We may have very different ideas about how to go about things but our intentions and ambitions are closely aligned. Different approaches to achieve the same ambitions are possible and the network should play an important role in supporting people to do what suits them; we are not one big homogenous group.

What is unique about NSUN is that we don't have a political position in the same sense as other organisations, or an organisational agenda. It really does come from a very personal place and personal experiences.

There have been plenty of ups and downs over the past 10 years, and many people in this room have shed their blood, sweat and tears, but we've survived and we have to keep moving forward. We have to change and adapt, not changing what's really important to us, but maybe how we respond to things, and how we organise ourselves. We need to learn new things, we also need to attract new people, new experiences as well.

Sarah shared some of the changes that have happened and that are planned, ►

"If we're talking about 'it's going to be done anyway' – then why not be part of the solution? The amount of experience and ability in the room is huge – so why not be their consultants, their advisors, their collaborators? Try and help them do the best they can. There are some brilliant people in here who are saying they already do it, and good luck to them, and keep working on that."

Debbie Roberts

Closing comments



I. Cluny MacPherson
r. Debbie Roberts

such as the recruitment process for new trustees, the repositioning process for NSUN and bringing in new energy and expertise. She also spoke about her own succession planning and a new management structure for the future, saying that although this wouldn't be her last NSUN AGM, it would be last one in the role of Managing Director.

Sarah extended her thanks to everyone, saying it had been a fantastic journey, with days like this reaffirming why she's been doing what she's been doing for so many years. She said that there were so many people to thank, so she would not go through a huge list. However, there were a lot of people who made the AGM happen. They include Zoe Kirby (organiser), Soka Kapundu, (finance manager), all of the trustees and those who are here today (Mark Wood, Joe Kelly, Julia Smith and Alisdair Cameron). She also thanked the filmographers

Russ and Sybil, Debbie Roberts, NSUN's resident graphic facilitator, musicians and tweeters extraordinaire Sarah and Rhiannon, speakers and Independent Chair Cluny Macpherson, for a great job chairing the AGM business. Emma Ormerod will be helping to evaluate the event, as well as reviewing the Members' Manifesto, which will be refreshed and published in 2019. Thanks to Mark Brown who has helped NSUN members to lift their heads a bit higher and to crystallise what we're doing, and look forward to the horizon.

Sarah finished by talking about the importance of protecting the past, taking action in the present, being together and supporting each other, and planning for the future.

Sarah also thanked the Mind engagement team for supporting the event and enabling it to happen. ●

"...but being able to collectively say: 'This is what we want and this is when we want it', moving forward more confidently and being able to communicate our uniqueness as a collective."

NSUN conscience

48 TOTAL RESPONSES

- 45 people agreed (or strongly agreed) that the purpose of the event was clear to them.
- 42 agreed or strongly agreed that they had felt able to participate in the event.
- 43 agreed or strongly agreed that they had felt listened to and their opinion had been valued.
- 44 agreed or strongly agreed that they had learnt new information.
- 46 agreed (or strongly agreed) that they had made new contacts.
- 44 agreed (or strongly agreed) that they felt more connected to the wider NSUN network as a result of the event.
- 46 agreed (or strongly agreed) that they felt more prepared to get involved to influence others.
- 47 agreed (or strongly agreed) that they felt they had received support from peers.
- 44 agreed (or strongly agreed) that they had provided support to peers.

1. THE PURPOSE OF THE EVENT WAS CLEAR TO ME

Strongly Agree	29
Agree	16
Disagree	2
Strongly Disagree	1

2. I FELT ABLE TO PARTICIPATE IN THE EVENT

Strongly Agree	23
Agree	19
Disagree	6
Strongly Disagree	0

3. I FELT I WAS LISTENED TO AND MY OPINION WAS VALUED

Strongly Agree	21
Agree	22
Disagree	1
Strongly Disagree	0

- "Didn't know what to say"
- "Didn't talk".
- "I didn't share my opinion".
- "I felt listened to – but as an employee of the NHS I actually, for the first time in my life, felt uncomfortable in a room of service receivers/survivors".

4. I LEARNT NEW INFORMATION

Strongly Agree	20
Agree	24
Disagree	4
Strongly Disagree	0

- "Interesting but nothing new".

5. I MADE NEW CONTACTS

Strongly Agree	19
Agree	27
Disagree	0
Strongly Disagree	0
No response	1

- "Best part of the day".

6. I FEEL MORE CONNECTED TO THE WIDER NSUN NETWORK

Strongly Agree	23
Agree	21
Disagree	4
Strongly Disagree	0

- "Actually feel more isolated from the network, but will hang around cos we are actually both on the same side..."

7. I FEEL MORE PREPARED TO GET INVOLVED TO INFLUENCE OTHERS

Strongly Agree	20
Agree	26
Disagree	1
Strongly Disagree	0
No response	1

- "am already 'gobby' "

8. I FEEL I RECEIVED SUPPORT FROM MY PEERS

Strongly Agree	30
Agree	17
Disagree	1
Strongly Disagree	0

- "from the other NHS staff at the event".

9. I WAS ABLE TO PROVIDE SUPPORT TO MY PEERS

Strongly Agree	20
Agree	24
Disagree	4
Strongly Disagree	0

What did you find most helpful about this event?

LEARNING/DISCUSSIONS AROUND PEER SUPPORT

- Meeting people and having difficult discussions about painful realities of peer support – people have conflicting views and that's hard but I think we have to face that to move forward.
- Meeting new people time to reflect personally in the work I deliver. You always learn from any event you attend if you are prepared to lean in to the discomfort.
- Hearing that the NHS is interested in adapting peer to peer as an intervention.
- Understanding what peer support really is or can be and thoughts on how the term may need to be reclaimed or renamed. A free and mutual support or paid work reframed by services?
- The different perspectives and understanding of peer support at local and national levels.
- By peer you have learned something new. Then you pass to your peer support as simple cooking.
- Learning about the Peer Support Charter was also very helpful; I've since written about it in my self-help charity's newsletter.
- I gained a perspective of a national peer support perspective and the views of this community on formal peer support.
- The theme and the format.

SPEAKERS

- The positive outlook of some of the contributions of the speakers.
- Keynote speaker. Afternoon speakers.
- Hearing the speakers – very inspiring.
- Mark Brown's message and Beth's were particularly helpful.
- Guest speakers.
- Some speakers were inspiring.

- Presentations and speakers
- Speakers.
- Listening to inspirational speakers.

SOLIDARITY AND SHARING

- Having beliefs and values cemented and echoed by others.
- Sharing experiences and ideas
- Sharing opinions, views and ideas.
- Information sharing.
- The group solidarity – the spirit of courage and the courage of spirit seeing people who talk about being broken looking like they are not broken (so it's not just me!)
- Connecting with others who have experience in peer support. Listening to people's experiences – it was inspiring.
- The feeling of being with my tribe! I felt energized and inspired by all the speakers and the buzz in the room. Seeing friends old and new.
- Solidarity with others. Facing difficult conversations about differences of perspective head on.

NETWORKING/MEETING NEW PEOPLE

- Networking
- Opportunity to meet up with peers and discuss issues.
- Good update on where NSUN currently is. Always good to network, meet new people and old.
- Connecting with others.
- New people/connections.
- The chance to reunite with old friend and make new ones
- networking opportunity.
- Meet & greet members & colleagues at the AGM.
- Meeting like-minded people and finding solutions.

OPPORTUNITIES TO SPEAK/ INTERACTION & INVOLVEMENT

- All was very useful. Being given

time to speak, I think was really good for me.

- That everyone was given the opportunity to speak if they wanted to. A variety of activities throughout the day.
- The sincere and absolute interactive nature. Audience all involved.
- One thing that stood out to me was the whole set of conversations between speakers and audience - openly ready to receive query, or different view or knowledge - not defensive but inviting and welcoming. This I believe is true united-ness, an inclusive feel rarely so openly felt in many a large gathering.
- The friendly and welcoming atmosphere and the fact there were many opportunities to listen to members' views and opinions and raise questions from the various speakers.

ENVIRONMENT

- Supportive environment
- The environment was friendly and enjoyable.
- The safe environment of being able to be open and honest

SOAPBOXES (X 3)

- Soapboxes with lived people experience
- Loved the 30 second sign to keep soap box to time!

OTHER COMMENTS

- The welcome. Varied food choices for dietary reasons.
- The ability of service users surviving their asylum throughout their time.
- Difficult to say as it was all very helpful. The very clear documents and information circulated prior to the event was extremely helpful. •

What did you find least useful about this event?

FOOD/REFRESHMENTS

- About the food choice. It could have been better and healthier.
- Piss weak coffee
- Ran out of coffee half way.
- The coffee ran out for a short period. Otherwise it was great!!
- No decaff tea. Surprising since most people recognise that caffeine is just another addiction. No fruit tea or soya milk for vegans.
- The food was horrible. I don't blame NSUN – I blame the college for its poor food options given our budget. I would have liked more time to discuss issues on our table.
- Halal food preference or vegetarian option.

BREAKS

- We have sat here without a break for over 1.5 hrs surely that is not good for wellbeing. We've been going for 2.5 hours now without a break.
- Breaks overran!
- The overrunning of breaks. It meant that less time was spent on the matter on the schedule and it felt very rushed at the end.

GROUP DISCUSSION

- Talks on the agenda – should have had more time for questions/ comments from the floor
- Not enough group discussion. Too much plenary discussion – loudest voices are always heard.
- Less of members interaction to the debate with key speakers.

ATTITUDE TOWARDS STATUTORY SERVICES

- The negativity about statutory services
- I'm a bit worried that peer support workers in the NHS might have felt undermined and/or attacked by some of what was said about co-

option. I am afraid of co-option but I think there's also a risk in leaving those working in and using the system behind. I'm not sure how much people in those roles felt able to participate in today's event.

- I'm a bit worried that the concerns some people expressed around co-option of survivor movement/ initiatives might have come across as an attack on people working within NHS systems - I'm not sure how supported some of the NHS peer support workers who attended.

PEER SUPPORT

- No clear answers. Need more insightful action that is not dependent on funds that can be withheld
- I would have liked to have more insight into the dynamics of peer support groups and how to provide a good support practice/ groups.

SPACE AND SECURITY

- I found having to be accompanied by security to the room quite disconcerting and anxiety-provoking.
- The rather confined feeling due to the security requirements of the building.
- The lack of space to move around between tables.

FEELING UNCOMFORTABLE

- I felt ostracised by my own community.
- I felt 'out of place'/ that it was not a comfortable place for me to be.

OTHER COMMENTS

- The train journey to get there. The fact that it was a 3 hour journey each way to get from home to the Conference did put a few of our members off. Fortunately 5 of us made it.

- My own fault - I sat on the a table with people I knew, I should have sat with people I didn't
- Start time, arrival by train at 10:45 am from Birmingham, for 10:30 am.

ANY OTHER COMMENTS

Comments regarding peer support

- I do not feel that you can learn to be a peer mentor. I feel their strengths lie in the experiences they've had.
- Sharing of good practice across the country of peer support should be an NSUN objective to have a link on their website introduced.
- How about finding ways of forming small support groups or people who help their peers one to one. Friendship and trust inner circle of referral by word and introduction (PSWs need a union). Not fighting please – DEVELOPING. Let us bloom and grow.

OTHER COMMENTS/SUGGESTIONS

- Tells us what you think - it would have been useful to have a neither agree or disagree box or a not applicable box.
- Would be nice to know what's next and what will you do with the event outcomes. Will they be made available to everyone?
- Would be good to have a graffiti wall all day to add comments, suggestions etc
- I would be very grateful, if you could keep me informed of anything which is going on with NSUN or other organisations. I'm interested in getting more involved. [NB: didn't leave contact details, so not possible to follow up].
- I like to get contact numbers off people or business cards.
- Is it possible to have more frequent regional meetings for NSUN members or explore ways in which we can share information or plan events/campaigns together. •

Other positive feedback



- | | |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none"> • Looking forward to 2019 AGM • Thank you to NSUN for putting on this event – great speakers and opportunities for participation. I'm really glad I came. • Thank you so much for organizing this brilliant event! • Very good atmosphere. Warm sense of togetherness, thoughtfulness and kindness. Concern for accuracy and inclusive approach. • V. Good. Zoe helped me out. • An extremely professionally organised event, but also very friendly and informal. Many thanks to the organisers. • Was excellent • This was best AGM & members' event for me out of 4. Well done to you. • Great day. Great venue. Overall welcoming and diverse energy. Thank you. | <ul style="list-style-type: none"> • Well done on not a good day for my mental health I felt safe, supported and inspired. • A huge thank you to all involved in organising this brilliant event. I found it to be professionally organised yet very friendly. I returned home feeling I was once again re-connected with the national mental health survivor scene. • Thank you for your efforts (before, during and after) in putting together a great day. • Christmas & festive wishes & happy new year. 2019 • Great atmosphere, fab and accessible venue close to station. It was all well thought through. <p>Thank you. ●</p> |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

Demographic Information

REGION

North East	2
North West	4
Yorkshire and Humber	4
East Midlands	7
West Midlands	7
East of England	2
London	9
South West	2
South East	3

AGE

18-25	2
26-35	4
36-45	4
46-55	12
56-65	15
66 - 75	4
75+	0

GENDER

Male	17
Female	25
Transgender	0
Other	0

ETHNICITIES:

Asian/Asian British Indian	1
Asian/Asian British Pakistani	2
Asian/Asian British other Asian background	1
Black British	2
Black British African Caribbean	1
White British English/Welsh/Scottish/Northern Irish/British Irish	30
White Other	4

SEXUAL ORIENTATION

Heterosexual	28
Bisexual	2
Lesbian	3
Gay	1
Other	6

NB: two people identified as 'celibate' under 'other'. One stated 'please put this. It's wrong to leave us out'.





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