



Annual general meeting and members event 2015

Held at The Conway Hall, 25 Red Lion Square,
Holborn, London WC1R 4RL

Thursday 29th January 2015 at 11.00am

The following report records the decisions taken at the AGM and the comments made in the various discussions, feedback forms, message boards and other forums.

Together we are stronger

AGM Business



Welcome and thank you

Co Vice-chair's **Sarah Carr** and **Dominic Makuvachuma** welcomed everyone to the meeting. Members, staff and trustees were all thanked for their continuing support. Sarah Carr informed the attendees that the Chair Kath Lovell had to give her apologies due to compassionate leave. Apologies were also received from Stephanie McKinley and Eleni Chambers, standing nominations to the Board of Trustees. Sarah Carr announced that this was NSUN's fourth annual general meeting and explained that the business would include asking members to:

- 1. Approve the minutes of the last AGM**
- 2. Receive the Annual Report and Accounts**
- 3. Vote new members on to the board**
- 4. Vote Honorary officers into position**
- 5. Approve appointment of Auditors & Remuneration**

Votes will only be counted if there isn't an obvious majority with a show of hands.

Item 1 Approval of minutes for 29th January, 2013 AGM

Sarah Carr asked for a true approval of the 2013 meeting. These were included in the Annual General Meeting and Members' Event report 30.10.13, page 2 to 4.

Julia Smith pointed out that on page 4 of the Annual general meeting and member's event it read that business closed at 11.30pm instead of 11.30am.

The Chair moved the motion to approve the minutes.

Tina Coldham proposed the motion

Peter Rogers seconded the motion

Majority approved

No objections

No abstainers

Motion carried.

Item 2 Trustees report & accounts

Members were asked to consider the statement of accounts and balance sheets of NSUN for the period ending 31st March 2014

The Treasurer's report summarised the income and expenditure for the financial year 2013/2014.

Income during 2013/2014 was £490,136 (2012/13 £494,202), which represents one per cent drop. The 95 per cent of income during the year was restricted funding to support specific work or Project.

Expenditure during 2013/2014 was £554,085 (2012/13 £467,363 an increase of 19% in line with the restricted funded projects brought forward from 2013.

The total reserves at the end of 2014 financial year was £23,475, made up of £2,039 unrestricted funds (2012/2013, £19,535) and restricted funds amounting to £21,436 (2012/2013, £67,889).

Hilary Myers asked if the Board was not concerned that the reserve is smaller this year than in 2012/2013 and that there was an increase of 19% in expenditure during 2013/2014 when there was less income coming in than the previous year. The Treasurer, **Mark Wood**, said it was not terribly concerning as most charities are in this same position but NSUN has fortunately got a reserve policy that is regularly reviewed. NSUN also had a Finance and Fundraising sub-committee that meets every two months to address issues in greater detail.

Cluny McPherson pointed out that there was a discrepancy in the audited accounts on page 5 of the annual report under heading “investment & other income” which read £23,116, and on the same heading in the audited accounts it read as £22,116. The Finance Manager apologised saying it was a misprint of figures and that it should have read as £22,116 as in the audited accounts report.

Andy Brooker asked if any work was being planned for regional and business development which was only 4% of the pie chart. The Managing Director, Sarah Yiannoullou, said priority was given to these areas of work. Work had already taken place at the beginning of the year in the North East region. **Stephen Crow** asked if there were any schemes starting soon. The Treasury, Mark Wood said the priority would be to be financially secure, thus being able to deliver further schemes. Mark Ewen asked if NSUN had any intentions of increasing project work in regional settings. The Managing Director said there was already a mixture of advisory work in some regions but this was not a consistent level across all regions. Any potential work depended on what income came into the organisation to support this.

The Chair then put the resolution that the report and accounts be received

Jo Josh proposed the motion

Julia Smith seconded the motion

Majority approved
No objections
No abstainers
Motion carried.

Item 3 Managing Director's Report

The Chair invited **Sarah Yiannoullou** to give the Managing Director's report. Sarah presented an overview of NSUN's work from 2013 to 2014 summarised on page 7 to 10 of the annual report. Some photographs of activity were shared to show the range of work covered.

Kato Walmsley said she felt there was a gap between communities and objectives. She said she would like to know which areas were getting what promotion and prevention and wanted to know what could be done to improve other areas.

The Managing Director, Sarah Yiannoullou said it very much depended on the focus of projects both geographically and objectives set by funding. The Manifesto content was the result of members' priorities across the country but the challenge was to reduce the disparity between individual experiences in communities and policy.

Gillian Goddard added that she felt that some of the gap was in schools and colleges and other similar places where young people could be encouraged and brought into networks to prevent and promote good mental health. She said acting early in one's life would prevent mental health problems from getting serious. Joe Kelly went on to say there were closures of much needed mental health services and people were not being included in commissioning thus not promoting prevention of mental health services. The Chair, Sarah Carr, said these were areas of concern for NSUN and work is being done on a regional level with Values Based Commissioning and other projects to look at work around all the serious issues going on.

Mark Ewen asked if NSUN would be interested in setting up an NSUN Commission in Sheffield given that it was very close to the Yorkshire and Humberside region. The Managing Director, Sarah Yiannoullou said the Annual General Meeting was intended to be in Sheffield last year in the autumn, due to waiting for some funding outcomes it was postponed and moved to this year in London. She said would like to focus on projects in all areas that had not much input from NSUN during the

previous years and places like East of England and indeed Yorkshire and Humberside would indeed be a priority among others. Further discussion and useful names of people in such areas and others not mentioned would be very helpful. She welcomed further discussion around these areas during and after the Annual General Meeting.

Item 4 Election of Trustees

It was explained that under NSUN's constitution trustees are required to retire in their third year. As this is the third AGM all trustees voted for last year would remain in post.

The following have indicated that they would like to re-stand for a further term.

Alisdair Cameron (third year)
Sarah Carr (third year)
Henderson Goring (Second year)
Kathleen Lovell (second year)
Clare Ockwell (second year)
Peter Rogers (second year)
Julia Smith (third year)
Dominic Makuvachuma (third year)
Mark Wood (second year)

● In addition the following appointments were proposed:

Eleni Chambers
Stephanie McKinley
Paul Valentine

Andy Brooker proposed the motion
Sue Poulter seconded the motion

Majority in favour
 None against
 No abstainers
 Motion carried.

● Honorary Officers

Chair: **Kath Lovell**
 Co-Vice Chair: **Dominic Makuvachuma**
 Co- Vice Chair: **Sarah Carr**
 Treasurer: **Mark Wood**

Kato Walmsley proposed the motion
Mark Ewen seconded the motion

Majority in favour
 None against
 No abstainers
 Motion carried.

Item 5 and 6 Appointment of auditors and remuneration

The Chair thanked the auditors, Martin Morrison and Co Ltd) and recommended their re-appointment. The Chair also suggested that the executive officer be authorised to agree the amount of remuneration for this year with the auditors.

Gillian Goddard asked how much would be paid to the auditors and how this compared to other firms. The Finance Manager, Soka Kapundu said £2,500 was the fee for the auditors. He went on to say there were a good value firm of accountancy, dealt with small to medium charities and were regulated by the Association Chartered Certified Accountants.

The resolution put to the vote, that the auditors are reappointed.

Peter Rogers proposed the motion
Cluny McPherson seconded the motion

Majority in favour
 None against
 No abstainers
 Motion carried.

The resolution put to the vote, that the Executive Officers are authorised to agree the amount of remuneration for this year with the Auditors, to the vote.

Mark Wood proposed the motion.
Jo Josh seconded the motion.

Majority in favour
 None against
 No abstainers
 Motion carried.

Item 7 and 8 Any Other Business/ Special Business

Co Vice-chair, Dominic Makuvachuma, said there was no other business/ special business at this meeting and declared the statutory business complete.

AGM business closed at 12.30pm

Soap boxes

Summary of key points from speakers. Key points made by each speaker are captured.



Dr David Crepaz-Kaey

“...I am very pleased and proud to be here as all this (the NSUN AGM) was a bit of my idea – the survivor movement has been going for a very, very, very long time, which is to say that even an old fxxx like me (and I can see others indicating themselves in the audience) have seen a lot. “10 years ago there was no NSUN, but today I was in a meeting with NHS England, who were talking about all the good stuff NSUN is doing. This is a real step forward: people acting together, mad people acting together, get noticed. “I want to reflect on the three reasons why I wanted to see NSUN before there was NSUN, and what the purpose of an organisation run by and for mad people is.”

First of all it gets us talking to each other. It is very, very easy for us to become isolated; it's very, very easy for us to become a set of individual problems, a collection of individual symptoms. It is much, much more difficult to ignore us as a voice of millions of people. We are here to network and to share our thoughts. “Secondly it is to build capacity – the frustrating thing about the survivor movement is that the people who would benefit most almost never get to hear about it. Of people who were in patients when I was, almost none of them got the opportunity to get a degree, get a doctorate, go to meetings or put on a suit. So many people get written off because of their diagnosis. “Finally, NSUN should not be, and can never be the voice of service-users, it should be a mechanism, and a tool and a catalyst, to make sure that every single individual voice of every single individual service-user can be heard – and is loud and is proud– in all our diversity and all our difference, for all time for all of us.” ●



Maria Bavetta

NSUN member and recovered service-user Maria Bavetta spoke on behalf of “Everyone’s Business,” (www.everyonesbusiness.org.uk) a coalition of over 70 UK organisations concerned with perinatal maternal mental health. She used a case history, “Anna,” to illustrate how maternal mental health can impact on women suffering from “the baby blues” and how poor current provision is. Anna was “struggling to get out of the house” and when she finally did manage to get to the GP, “all that happened was that she was prescribed antidepressants.” She was “crying all the time” and frightened to tell anyone about her thoughts in case her baby was taken away from her. When her baby was eight months old, and Anna needed to be admitted to a Mother and Baby Unit, Maria Bavetta stepped in as part of “Everyone’s Business” – an organisation campaigning for accountability at a national level for the provision of Mother and Baby units, so that a Mother can remain with her baby. As Maria said: “Every area of the UK should follow the NICE Guidelines for ante and perinatal mental health published in December 2014.” All health system and social care workers should have specialist perinatal/ compulsory training. Across the UK we are 60 beds short (that means many more than 60 Mothers, as there is a turnover of occupants) and 50% of the UK does not have any services for Mothers and Babies needing mental health care. This is despite the relatively low cost of this provision, estimated as 0.0000023% of the total health budget of £8.1 billion for Mother and Baby care. To quote Maria: “Let’s look after our women.” ●



Paul Valentine

“What’s happening in 98 days’ time? I think we know,” said Paul Valentine. And yes, we all knew that there was an election. Paul had therefore searched for mental health on the websites of the main five political parties, using their search facilities.

Tories had nothing on the site; UKIP “health yes, mental health, no.” Labour, using Google to find the site, nothing on the website, so used Google and put in mental health and was redirected back to Google – “what does that tell you?” Lib Dems: “We’ve had a lot from Nick Clegg and he’s personally to be congratulated” but although championing mental health, Paul said there were not policies but priorities. Since mental health has been a priority, spending of money on mental health for young people, “including the almost fraudulent use of money for EIP, has been nothing short of a national scandal,” although the Lib Dems had at least to be congratulated on “raising the profile” of mental health. However, the Green Party was praised, although Paul “had to declare an interest as I am a member of the Green Party.”

He said that the Green party website had information but it “was not all good” as mental health came after health, rather than within it. There were “clear and comprehensive policies” which encouraged co-production with service users, and it was clear that the policies were “written by service-users” and “not experts by PR.”

Paul says that: “We should look to be part of the co-production agenda. It is now time to stop reading the agenda. It is now time to start writing it.” Paul encouraged everyone to get involved at a local level to make a difference, and reminded them of the quote: “If you always do what you always did, then you’ll always get what you always got.” ●



Hannah Macdonald

Hannah is a qualified nurse, who worked on an HIV ward but since 2007 has been in mental health services, with most of the time spent on a mixed sex ward. There she was “financially and sexually exploited” and felt “lonely and unsafe,” losing both her self-respect and her dignity. She was then sent to a therapy community which was the “complete opposite.”

As a result of her own positive and negative experiences, she is now gathering other people’s experiences on mixed sex wards, with the support of NSUN. Her intention is to use the evidence she collates to influence commissioners to improve the care of people in inpatient units. Hannah has created a questionnaire with NSUN’s help and is asking for any NSUN members with experience of inpatient care on a mixed sex ward, whether good or bad, to respond themselves or, if they know someone else who is/has recently been on a mixed sex ward, help them to complete a questionnaire. Hannah will be giving feedback in June 2015. ●



Ajay Sawney

Ajay commented on research saying: “The mental health industry is spending a lot of money on research, and I read quite a lot of these guides. But I don’t hear anything about these key words - nothing about pessimism, inactivity, loser, decision making - therefore I find this research very ineffective.” ●



John Viner

John is an ex service-user/carer who is also an involvement worker for Hounslow and for Voiceability, and involvement in Ealing. John talked about hope in the mental health services, drawing a parallel with the Greek election victory, as “an example of ordinary people getting together and standing up.” He wanted to see a campaign in the UK, and referred to the Trade Union and Socialist Coalition (TUSC) and the “No cuts, no austerity programme.”

John has been working in mental health for seven years, during which time he has seen “360 degree attacks on mental health service-users.” These include closure of day centres and acute wards, and John says that we “cannot afford to see any more acute beds close because: “They are killing our people that’s what they are doing.” He talked about unsafe discharge because of bed pressure, which he describes as: “playing Russian roulette with those people.” He said that staff “have to make life or death decisions” for those people, and they themselves go off sick as their case loads are doubling.

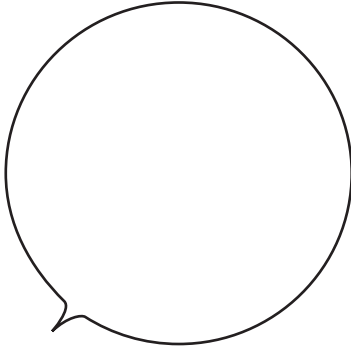
He went on to talk about the threatened closure of the only 365 days a year centre in Ealing, the Solace Centre, and the closure of other day centres, despite the demand for them from service-users. He said that this lack of services leads to suicides: “People die because they have had those services taken away from them.” He called for an online campaign about closures of day centres, with a dedicated website: “We’ve got to stop it.” John finished by saying: “An injury to one is an injury to all.” ●



Joe Kelly

Joe’s platform was “about power and influence.” This means having a seat at the table, as in “Article 29 of the UN Human Rights Convention, the rights of people with disability, which is about access to the political process.” It is also about “framing our own agenda, not accepting what others are handing to us, and then wondering why it doesn’t work.” Joe has mobility difficulties, as well as being a long term survivor of mental health problems, so says: “Being double disabled, I see the power of pan disability and a holistic approach.” As he says, if you are not born with disability you acquire it in your life time when you get to old age.

He also talked of: “changing society,” which is quite complicated. He sees it as “a multi layered-cake, with MPs and lords at the top, professionals, business people, councils, education.” It was important to “speak our loudest” in the time coming up before the election, when politicians of all parties are ready to listen. He sees change being the result of long term efforts – “a marathon rather than a sprint.” He called for: “greater investment in the power and influence thinking and activity.” ●



Liam Kirk

Liam introduced himself as a psychiatric patient in the “22nd year of his psychiatric career.” He reported on a conference the previous day (28 January) staged by the West London Mental Health Trust. The conference subject was the efficacy of medication. It featured speakers of national and international reputation. These included one of the Trusts’ leading medical advisors, Dr Michael Myers, regarded as a very influential consultant psychiatrist. Dr Myers responsibilities also include Broadmoor and input to parliamentary panels. Dr Myers said that the NHS considers success as patients being medicated for the long term not the short term: the “continuous adherence to their medication regime.”

Success is:” not measured in patients recovering,” and returning to the life they had before coming into psychiatric services. To the neutral observer, a “practical benefit of psychiatry” would be measured in “the employability of those who came into contact with psychiatric services.” However, Liam reports that Dr Myers: “does not see it as part of his job specification that patients return to the work force.” Liam also reports that Dr Myers does not see it as the responsibility of the National Health Service “that 2.3million people in the UK claim welfare benefits for mental health conditions.” ●



Nigel Moyes

Nigel has been an NSUN member for over five years, and a volunteer in the Eastern Region for at least two and a half years. Nigel says: “The biggest thing NSUN has given me, and I’ve been using services for the best part of 25 years, (up until last July,) is confidence. It’s also given me the right to challenge the big players.” Nigel has been involved in training, and has delivered training; locally in Suffolk he has chaired two events a couple of years ago. He also “had the privilege of being involved with the Mental Healthwatch book launch, and has a case study in there. This was a transition from being involved with his local link. Nigel thinks it is important to remember not only the service-user voice but the carer voice, and also the whole community voice – in fact the whole country voice.

Through fronting those events, Nigel became involved in Suffolk User Forum, an independent charity, which looks at gaps in services. “NSUN has given me the chance to raise that grass roots level voice to a national level.” Nigel wants to challenge NSUN to do more peer mentoring; he believes that there are ways of supporting peer mentoring without a physical presence from NSUN, using 4PI. Nigel has also recently become involved with Recovery Colleges (IMROC model) and emphasized that there can be no health without both mental and physical health. He also co-chairs the Suffolk Dual Diagnosis Forum because statistics show that a lot of people use drugs or alcohol to self-medicate for their mental health problems. He has also recently become a peer tutor in a Recovery College “being able to give something back.” He feels that “the only way forward is that we have an equal footing through co-production and that service-user involvement is not seen as tokenistic. ●



Daisy Abrahams

Daisy, who studied law at university, spoke about the law and rights, and how this applies to mental health, discussing the relevance of human rights legislation. She specialized in human rights, and believes that she has seen a loophole or a “lacuna” in the interplay between the Human Rights Act and the Mental Health Act.

Human rights came into domestic law in 1998 in the Human Rights Act. The Mental Health Act predates this, having come into force in 1983, although it was reviewed and amended in 2007, to introduce advocacy as an enshrined right. Daisy says there is a “constructive tension” between these two acts, but that the Human Rights “trumps” the Mental Health Act – all other laws are below the Human Rights Act. All laws have to be read in line with Article 9 of the Human Rights Act – Article 9 refers to Freedom of thought, conscience and religion. ●



Adrian Wyatt

Adrian talked about international human rights, referring to Diane Mulligan who is the UK rep on the United Nations Disability Committee, which is trying to co-ordinate all of the different conventions.

He said that if, after going through the Disability Committee you were still dissatisfied, then you could appeal to the general Human Rights committee and then the General Committee of the United Nations. ●



Mark Collins

Mark introduced himself by showing a piece of paper on which he had written: “I’m not allowed a psychiatrist, I’m anti- bullshit.” He spoke about the Convention on the Rights of People with Disabilities – the Disability Rights Act.

He went on to talk about how in the early 1900s there was a move in European and American psychiatric circles to purify the world by using Eugenics. Fast forwarding to the second world war, he described how German psychiatry instituted a euthanasia programme, “taking people away from their homes in black vans.” Catholic Bishop Clement spoke against it and “amazingly” the Nazis stopped the programme of taking people with mental health problems away from their homes. “But our brothers and sisters were being killed in the asylums.” On National Holocaust Memorial Day “nobody mentions those people... we should remember them, along with the Jews, along with the gypsies – it’s never mentioned.”

Fast forward again to the 1948 the Universal Declaration of Human Rights: “that’s for all of us, we’re all human.” He thought that 4PI was a “brilliant initiative,” because it enabled service-users to influence their care and policy. He ended by saying that: “everyone in this room needs to know about rights.” ●



Sarah Holmes

Image “The government needs to look at how much it is actually spending on containing people with mental health problems and put it to something more proactive.” Sarah talked openly about her own experiences: “I spent nearly three years in psychiatric units. I fractured my spine in a failed suicide attempt, I almost lost both of my legs, then they sent me to a private unit.

All that money – they spent £450 a day to send us to the Priory and in reality the things that helped were actually the people. It was the people who cared, that showed some compassion that got me well enough to get me out of hospital. “Being out of hospital, the things that keep me going now are being involved in things, some of the things that NSUN does. I’m involved with my local NHS Trust and I do bits and pieces with Young Minds. But do you know what, I still get days when I think I just want to go to sleep and never wake up.” She says that when she thinks about doing something harmful at night, she is stopped by the thought that she has to do things in the morning, and cannot let people down.

She says that if she didn’t have that structure: “I could easily just lie in bed and feel sorry for myself all day.” Sarah therefore thinks that: “... they need to put more money into projects like NSUN, projects about involvement, about improving services, that aid recovery.” She says she is now not in hospital “anywhere near as much” which must save money, when compared with when she was an inpatient and in A&E all the time. She puts this down to NSUN: “It’s through organizations like this ... there needs to be more money and it should be put in there.” ●



Anne Beales

Anne firstly restated the parameters for a new vision statement for NSUN, as given to all those attending the AGM. She included the aims of facilitating active links between service-users, building capacity of service-user groups, brokering and facilitating access for the purposes of influencing. She also looked at NSUN’s values and relevant aims: “to be open and transparent to support service-use organizations, not replace or supersede them” ... and to give a voice to seldom heard groups, to respect equality and to value diversity. She also talked about the activities that NSUN could add to the service-user movement. She went on: “One of the things I wanted to say is that the reason we chose a network is because a network is a non-hierarchical organization.” Service-users had had enough of doctors know best, nurse knows best: “We wanted an organization that was ours” and in which whatever anyone said, wherever they came from, it was valued. “Networking works and it’s important for NSUN to talk about the links it has with other networks,” nationally and internationally. We can learn from these links: international peer support workers are saying “please don’t make the same mistakes we made, where many peer support workers are low paid and stuck in dead end jobs.” They are being asked to substitute themselves for nurses or social workers. “We need to avoid the pitfalls of where peer supporters are having to get certificated to become a peer support worker.” She also said that we can learn from other countries. For example, in New Zealand they have service-user led respite units, and schemes which help people who are in distress. “International hands reaching across the water is very, very important.” Anne stressed the importance of the peer to peer network that can reach out and share lessons like these. ●



- Service users and survivors are validated and empowered.
- Service user experience is valued and used as the basis of decisions made by funders...
- Power, human rights and choices are returned to service users.
- Everyone's voice is heard, including those not reached by traditional methods.
- There is a recognition and appreciation of the diversity of service users, their views and experiences.
- All personal narratives are respected and accommodated.
- Banish stigma – in the workplace and in the media e.g. around benefits.

- There is a move away from the hierarchical medical model of mental illness.
- Mental ‘illness’ is no longer understood in terms of individual pathologisation, but is seen instead as a valid response to life experiences (e.g. loss of job, poverty, poor housing, bereavement, abuse and neglect).
- Person-centred care and recovery replaces the ‘meds and beds’ approach to care.
- There is a recognition that there is no ‘one size fits all’ answer or approach.

- Co-production becomes a reality and is rolled out across the UK.
- Service design involves service users and survivors at all stages of the process.
- Service user involvement in interview panels, training, policy making etc.
- Service user and carers teams ensure that everyone who wants a say gets a say (not just to people who are going to agree with what professionals have already decided).
- There is an open dialogue approach between all parties involved.
- Experts by experience are valued and paid for their involvement.

- Consistent mental health services across the UK.
- Improved waiting times across the country.
- No 'revolving door' patients who are discharged before they are ready and who don't have recourse to support upon discharge.
- More community services in the community.
- Timeliness of interventions.
- Development and promotion of peer support.
- Payment and validation of peer support workers.
- Service user care plans should be co-designed.

Stronger Networks and Information Sharing

- All service user organisations are joined up by one platform.
- Expertise is shared via connectivity (meetings and social media).
- Good practice is shared and replicated across the country.

What Needs to Happen? / What should the next government to do?

Funding

- More funding, not less. Bring funding for mental health up to the same level as physical health.
- Stop benefit cuts and austerity measures.
- Fund long term talking treatments for victims of abuse.
- Stop cutting services for young people.
- Funding for drug free talking therapy.
- Free up £ from health block contracts for personal health budgets.
- More localised funding.

‘CCGs and HWBs are not using the BCF in the way it was intended - namely for better care - meaning drug free talking therapy. The crisis in the NHS is caused by toxicity - over-medicalisation.’

Human Rights

- Listen to, respect, involve/engage and fund service users in the long term
- Demand rights – United Nations Charter for Rights of Disabled People.
- Repeal/reform of the Mental Health Act.
- Address the UN Convention on the Rights of Persons with Disability (UNCPRD) and how they will abolish/reform the mental health act as a result to make its provisions a reality for users/survivors as part of a wider disability community.
- Reduce stigma.

‘The area of section 17 - leave from the ward should be more flexible and kind to the patient – physical restraint can be an

unnecessary distress on the mind [...] Service users should not be abused by compulsory treatment orders that can often cause unnecessary distress (and possibly suicide) and hinder recovery; but money spent on Day service provision (which is much much cheaper than hospitals) and can offer continuous assessment in the community’.

Services

- Have more talking and complementary therapies to aid people overcome their distress and suffering.
- Reduce over-medicalisation e.g. prescribing antidepressants.
- Provide peer support – and pay support workers.
- Early intervention.
- Bridge the link between child and adolescent services.
- More access to crisis services.
- Save our day centres, drop-in centres and acute beds!
- Access to records.
- Services should travel to you. Turn the buildings over to social housing and get mental health teams to travel the community in a bus!
- Instead of prison and restriction, and hospitals that are distressing and re-traumatise, we need to explore alternatives.
- Choices and information should be provided clearly and meaningfully.
- Service design should involve service users and survivors.

‘The one thing that stands out for me is that access to peer support should be provided. That's what made the most difference for me. It does need to be enabled though. Peer supporters can be exploited and expected to work for nothing.’

‘I think the government should make mental health a priority in healthcare. You are put on a waiting list and just ignored until you reach the top of that list (which can be months or even years). In other areas of health there are time limits for waiting lists in mental health this is not the case, why not?’

‘I think there should be a mental health professional available to every single A&E department instead of being treated like a hot potato with no one willing to take responsibility and passing the buck to whoever they can rather than deal with the mental health patient in severe distress’.

Research & Training

- More research/info about the long term effects of medication and poor efficacy.
- Share best practice.
- Training in diversity on mental health in workplaces, with commissioners, GPs and practitioners. This should be designed and delivered by service users.
- Parenting skills – support, role modelling, prevention.
- Education in schools.
- More training for school staff.
- Training for carers, volunteers and mental health workers.
- What should NSUN Do?

Values/Ethos

- Protect service user-led culture and ethos.
- Be a ‘curator’ / spokesperson for all service user voices.
- Ensure that the voice of experience is not merely accepted, but is positively valued.
- Avoid following anybody else’s diktat.
- Challenge tokenism.

Networking

- More real world networking and meetings to help us feel empowered and connected when

we go back to our own areas of the country.

- Skills share across the network.
- Peer mentoring.
- Regional champions and ambassadors.
- Build alliances with other disability groups, regionally and locally.
- Work in alliance with national carer organisations.
- Develop effective strategies to effectively engage with young people in our work, e.g. offer free pizza!

Capacity Building

- Value the membership and utilise their skills, experience and abilities.
- Capacity building outside of London – motivate more groups to get involved.
- NSUN base – office NE England.
- Facilitate local area groups to have meetings.
- Sustainability of user led groups.
- Encourage people to vote e.g. by engaging them with the NSUN Mental Health Manifesto and challenging their feeling of disenfranchisement.
- Regional campaigning hubs to bring people together so they don’t fritter their energy with disparate and disjointed action.

Involvement and Influencing

1. Campaigning and Lobbying

- Greater focus on mental health activism and engagement with politics.
- Challenge hierarchical medical model and involve service users more in alternatives e.g. educational initiatives like Recovery Colleges.
- Be much more critical of what the ‘psych’ disciplines believe in.
- Promote values-based practice as a way of challenging the medical model.
- Campaign for the Mental Health Act to be repealed/reformed.
- Campaign against benefit cuts and austerity measures.
- Lobby for a Minister for Mental Health.
- Communicate a clear vision of what NSUN is and what it stands for.

2. Research and Training

- Consult with members and collect stories of people’s experiences.
- Design and deliver training to CCGs, GPs and other mental health workers encouraging

equal involvement and partnership in recovery.

- Document what is happening e.g. in terms of waiting times across the country and use this information to shame politicians into action. Also highlight evidence showing the 'postcode lottery' in terms of waiting times across the country. Make training in mental health issues mandatory for GPs so they better prioritise this in their work.
- Document the extent of service users who are discharged too early and become 'revolving door' service users and the lack of support available to them. But we also need to think more about what actually helps them once discharged, beyond keeping them in the psychiatric system.
- Develop media resources to educate journalists in their coverage of mental health issues.

3. 4PI

- Working towards national standards of good practice.
- Develop a strategy for the development and implementation of the 4PI framework.
- Independent auditing of 4PI to ensure quality and adherence.
- Use 4PI to galvanise mental health service users and other disabled groups to take collective action.
- Take a diverse community-led approach to 4PI.

Evaluation

What did you find most helpful about this event?

1. Information

- Information and talks
- What NSUN is about. 4PI. Very good model if it can be implemented.
- 4PI and Andy
- Information. Meet people who work and members from NSUN.
- Learning about NSUN's work and the 4PI initiative
- Launch of 4Pi and hearing the soapbox sessions and networking
- Hearing about all the activities NSUN have been doing
- Solidarity with other SUCs and hearing about NSUN work.

- Soapboxes
- Soapbox – networking.
- Soapbox was great!
- Soapboxes

4. Good atmosphere

- Good atmosphere. Lots of input from all present
- The positive manner the event was held. The encouragement and freedom of association where no stigma was attached to having a psychiatric condition. The atmosphere and spirit of the hall helped to lift my mood.
- Great people and place – venue – but it does need to be North.

5. Accessibility & diversity

- Accessibility
- Info pack
- Audio settings
- Diverse views

What did you find the least useful about this event?

1. Lunch

- The shoddy attitude of the so called 'caterers' and the lack of choice and quantity of food available. NSUN resolved this!
- Food was scanty
- Food!
- Not enough lunch!
- Sandwich deficit.
- Lunch (initially)
- Lunch
- Sketchy caterers!! I can say because I grew up in this industry and worked for many years, Sorry!

2. Discussion around carers & service users

- Being heckled by carers who think NSUN should be for them and dominated the group.
- Last session – vision. I thought facilitator should at least listen rather than having personal comments. Found it very disappointing when we were having our vision where (facilitator) was not co-operative when it was mentioned – carers should be equal partners – carers were out rightly dismissed – felt devalued – disrespected.
- In our Vision table felt not listened to when

pointed out that working together as service users and carers – told ‘NSUN is service user only organisation there are plenty of carer organisations around’.

3. AGM Business

- Accounts
- Morning session might not be so important or interesting for some people who might find a whole day too long.
- I thought the AM session could have been sped up a bit

4. Temperature of the room

- The temperature of the hall. Some found it very chilly.
- Thought the room a bit breezy as in chilly. [Symbol]

5. Length of day

- Too long a day.

6. 4PI

- Don't really see how the 4Pi is adding to the existing initiatives or how it will contribute to more user involvement.

7. Nothing creative to do

- Too much talking – nothing creative to do. How come we were not invited to go up to the drawing board – nothing to colour in – it felt a bit like them and us and it drove me round the bend!

8. Timing of event

- Held on a week day – bound to clash with something. Should be held on Saturdays (or Sunday afternoon). Could therefore only attend end.

Other comments:

- Hashtag on all slides, so everyone can contribute to a live feed that can be viewed by those unable to attend.
- Why was the music so quiet?
- A pity more people did not attend – I wonder why? Loads of people in London area could have got here easily. Lots from Croydon, but not everywhere else.
- Personality disorder diagnosed – though a recognised form of mental illness.
- More regional events
- Soapbox – more time for these and longer session – 4 mins each is fine!

Appreciation?

- Good location, great support, the event was very informative.
- Thank you - as always!
- All very well organised and relevant. Thank you!
- Great venue – easy to get to and nice big hall
- NSUN is one of the few organisations where the service user/patient/client voice is heard. Unfortunately Mind, Sane and Rethink cannot truthfully claim to speak for the interests of patients and their families. Next time perhaps there'll be talk around repealing of the Mental Health Act
- First NSUN AGM met service users. Found it quite interesting. Hope to get involved and get support needs.
- Had a wonderful time. Thanks.
- It's always like coming home...well done.

Thank you