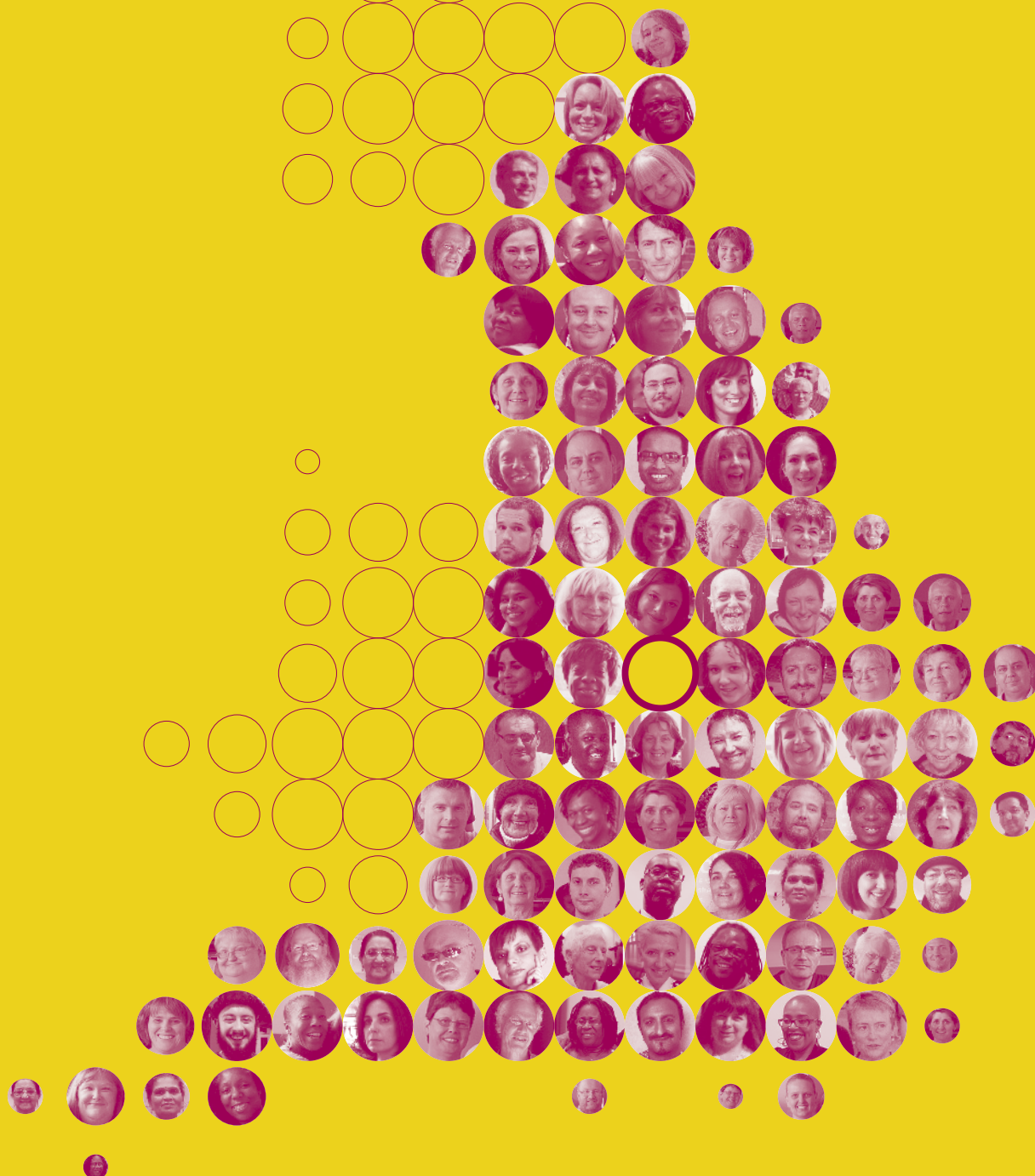


# Annual general meeting and member event

NSUN national gathering  
and Shaping Our Lives  
launch event

The Centre for Voluntary  
Action – 138 Digbeth  
Birmingham. B5 6DR

Weds 8 June 2016  
10.30am – 4.30pm





## Decisions & discussions - Soapboxes & feedback

## NSUN national gathering and Shaping Our Lives launch event

**The Centre for Voluntary  
Action – 138 Digbeth  
Birmingham. B5 6DR**

**Weds 8 June 2016**  
**10.30am – 4.30pm**

**National Survivor User Network**  
**Riverside House**  
**27-29 Vauxhall Grove**  
**London, SW8 1SY.**

**Telephone**  
**020 7820 8982**

**Email**  
**info@nsun.org.uk**

**Website**  
[www.nsun.org.uk](http://www.nsun.org.uk)

**Registered Charity No.  
113598**

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User Network 2016

# Welcome and thank you



NSUN co-chair **Dominic Makuvachuma** chaired the AGM, welcoming everyone. The meeting is a decade since NSUN was formed at the “Doing it Ourselves” conference in Birmingham in 2006.

“We can say with pride that lasting for 10 years is becoming more and more rare for a third sector organisation of our profile and nature,” said Dominic. “We need to celebrate that. Both veterans and new blood need to aspire to be relevant, and keep the fires burning. It’s all about thriving and it feels like we’re now starting a new set of challenges.”

Graphic facilitator: **Debbie Roberts** explained that she would be capturing the day in a visual using words and pictures (see above.)

**Anne Beales**, who was part of the original management committee for NSUN back in 2006, urged people to “absolutely know their own history,” by understanding the history of the survivor movement itself. “NSUN was set up so that we could tell the mental health professionals who our leaders are, not let them tell us. There are three things we must remember: to remain independent; to have the direct voice of people; to act as a collective. If we remember these, and our history, we will succeed.”

**Keri Lawrence:** from South Staffordshire Network for Mental Health, who is new to NSUN, gave his first impressions: “It definitely feels like there is a lot of charisma, energy and passion in the room, and we really want to be part of that. We are almost like a localised version of NSUN and want to feed our members’ problems that need to be dealt with at a national level into it.”

## About passion not money

Dominic said that NSUN was “under the cosh” financially but “it’s never been about the money, it’s about the passion. We’ve always been about the support, the collective that Anne Beales talks about. It is about creating a flat structure and only looking up to the people who look up to you. Everybody has got something important to contribute and if we stay with that spirit, we **WILL** thrive.”

Members, staff and trustees were all thanked for their continuing support. Apologies were received from the following: trustees - Eleni Chambers, Paul Valentine, Sarah Carr and Clare Ockwell; and from David Crepez-Keay and Catherine Haigh, chair of North East Together. ●

## AGM Business

1. Approve the minutes of the last AGM 2015
2. Adopt 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 to be counted only if there is not an obvious majority with a show of hands.



## Our business



### Item one

#### Approval of minutes for Jan 29, 2015 AGM

**Dominic Makuvachuma asked for a true approval of the minutes of the 2015 meeting. These were emailed to attendees and a copy was included in attendees' information packs.**

- **Julia Smith** proposed the motion
- **Cluny MacPherson** seconded the motion
- **Majority approved.** No objections. No abstainers
- **MOTION CARRIED.**

### Item two

#### Trustees' report and accounts

##### Chairs' report/annual report

**Sarah Yiannoullou**, NSUN MD, welcomed everyone and mentioned the chairs' report on the first page of the annual report. There the co-chairs, **Dominic Makuvachuma** and **Sarah Carr**, talked about the successes and challenges and highlighted that we want to be a "feather in the cap" and a "thorn in the side" (of mental health services) and that "that's very much how it's felt with NSUN. There's lots to celebrate but we need to be challenging, we need to be edgier and we need to do a bit more campaigning and shouting."

##### Treasurer's report and finances

**Mark Wood**, treasurer, stated a full copy of the 2014/15 accounts was available (at the back of the room and was emailed to attendees) which includes an examination by our auditors. He went over the main highlights as follows:

Income during 2014/2015 was £408,495 (2013/14 £490,136) which represents a drop of 17%.

Expenditure during 2014/2015 was £374,031 (2013/14 £554,085) a decrease of 32% in line with the decrease in income.

Surplus in 2014/15 was £34,464. (2013/14 deficit of £63,949) was added to the reserves of £23,475, which were brought forward from the previous year.

Reserves carried forward to 2015/16 was £57,939.

Income was mostly from grants from a variety of sources. Expenditure mainly staff costs. Any questions? (none)

The financial position of NSUN for the year 2015/2016 is secure, with reserves of £57,939 brought forward from the previous year.

NSUN secured funding through grants of £392,579 to cover planned expenditure in 2015/2016.

2016/2017 has a secured budget of £370,657. Income sources include grants, contracts and hosting fees.

Mark emphasised that things are bit precarious in terms of finances. Trustees are looking at ways of expanding our funding sources including donor funding. So if anyone has any spare cash, then please go to the fundraising part of our website to donate! Any questions?

**A member** from the floor asked how Brexit would affect us funding-wise. Mark said that we don't get any funding from the EU so it won't affect us in that respect.

**Another member** (name not stated) suggested charging a minimal fee for membership and that this works for lots of other organisations. Mark Wood said that the trustees had already considered this in the past, and will certainly look at it again.

Sarah Yiannoullou added that they had already been looking at different types of membership charges especially for groups (not service-user-led groups) but other larger organisations that use NSUN's services and advertise opportunities with us.

**ACTION:** trustees to review introduction of membership fees.

**The chair put the resolution that the report and accounts be received.**

- **Larry Gardiner** proposed the motion
- **Majority approved.** No objections. No abstainers.
- **MOTION CARRIED.**

### Item three

#### Managing Directors report

Sarah Yiannoullou went through the Managing Director's report - what happened in 2014/15, stating that we've remained true to our original aims of networking, capacity building, and involvement and influencing. In the annual report 2014/15, from page 5-9, there's a detailed list of activity that happened over that period. Highlights:

##### 1. Networking

"We continued to facilitate and help organise local and regional events. We said that would be a focus for us because members were clearly saying they wanted more local presence from the organisation. But it's not just about NSUN people being present, it's about how we help facilitate and mobilise you to organise things in your area to connect to the national. We ran regional, national and international events. With Together (Wellbeing for Mental Health) we hosted the International Initiative for Mental health Leadership (IIMHL) exchange for Peer Support and Service User Leadership. We held an event at the Ortus Centre in London and ran a workshop and presented at the IIMHL conference in Manchester. We also continued to put out our e-bulletins, 60+ bulletins were sent out during that period, and producing newsletters, briefings, and social media."

##### 2. Strengthening service user groups (capacity building)

"We delivered over 80 presentations and we ran 30 training events. We also organised and facilitated over 270 meetings, and involved 1,644 people to give an idea of the amount of activity we were involved in. We also launched individual member campaigns and blogs, thanks to anyone in the room involved with those, and we hope to strengthen that over the coming year.

The briefings and the guides have been important, and we started talking to Mark Brown from Social Spider who is helping us think about how we develop briefings for organisations so we can help you (as organisations) to do some of the work that you may not have time to do or don't have the mechanisms to get that info as easily as a national organisation might. Resource and



# Our business

information sharing is really important and responses to our member survey said that was one of the most highly valued functions of NSUN, getting that info regularly and it being very current. The bulletin always comes out as the highest scoring service we provide.

Signposting is also really important. We obviously don't know everything, can't do everything but we usually know someone who can help. Research is also an important area we want to develop in making sure that peoples' experiences and messages are communicated, a credible way and robust, so the methodology that we use to bring peoples' information and experience together and then communicate on is an area we are working strongly on."

## 3. Involvement and influencing

"In 2015, we launched the members' manifesto, which incorporated a lot of feedback from the last AGM. There's a lot that can be improved on and we're working on that. Today's soap boxes will help to feed into the final document.

Policy meetings – we're now recognised as a national organisation. We don't get invited to everything but we get invited to a lot. We were invited to input into the Mental Health Taskforce report along with a number of other national organisations.

Members' comments and priorities were fed in to the process and positively influenced both the tone and language around equalities and rights.

We get a lot of feedback from members through polls and requests through the bulletins and that helps our contributions to be more credible and have greater impact.

Commissioning is obviously a very important area. **Emma Perry** and **Naomi Good** have done a lot of work on this. The MAD Alliance started in July 2015. It's a really successful, local piece of work where 32 advisors, people with experience of using services and carers, feed into influencing local work and decision makers.

## 4. 4Pi National Involvement Standards

"The launch of the 4Pi standards was a really significant piece of work for us. It is the culmination of not just three years but more like 10 to 20 because we were building on the work that has been done before, so bringing together and collating peoples' products they had developed but also peoples' experiences of being involved or involving others."

**Alison Faulkner:** "We've been doing some really exciting work with a number of different organisations and different ones take it up in different ways...But it's been exciting, and also working with Debbie (Roberts, graphic facilitator) has helped us find new ways of taking the standard to orgs. If anyone is interested in us working with you on 4Pis, please let us know. This simple framework can really work."

**Mary Nettle:** 4Pi has been signed up to by the University of Worcester (where I live) thanks to the work of the impact group. So now this nationally approved structure is embedded and it's made a lot of difference.

**Sarah Yiannoullou:**

**"I just want to finish by saying thank you very much to everybody and to the staff. 2014/15 wasn't the easiest of years because there was a lot of uncertainty. But the commitment and the dedication was just above and beyond what was expected so a big thank you to everybody - volunteers, consultants, trustees, members, everybody."**

# Item four Election of trustees

**Sarah Yiannoullou:** The articles (of association) state we have no less than 3, no more than 12 trustees. There are some skills that the board needs. Following the AGM, we will do a skills audit of our current 10 trustees and then we will put out an advert for the remainder. There are a number of trustees remaining on the board who don't have to be re-elected because they are still within their three-year term, and there are a number of trustees that we need to vote on today:

**Remaining on the board are:**

Eleni Chambers, Henderson Goring, Stephanie McKinley, Paul Valentine and Mark Wood.

**Trustees nominated for re-election are:**

Alisdair Cameron, Sarah Carr, Kathleen Lovell, Julia Smith, Dominic Makuvachuma.

**Resigned:**

Claire Ockwell, Peter Rogers.

**To note:**

Mulimba, who was our admin/office manager, had to leave because of ill health.

**We now propose the motion to vote on the re-election of Alisdair Cameron, Sarah Carr, Kathleen Lovell, Julia Smith, Dominic Makuvachuma.**

- **Nigel Moyes proposed the motion.**
- **Mish Loraine seconded the motion.**
- **Voting: Majority approved. No objections. No abstainers.**
- **Motion carried.**

**Question from Fiona Wright:** What do people do if they don't want to say something themselves? Some people may want to find someone to talk to who can speak for them to express their views in that way.

**Question from floor (name not stated):** Question in the way that you vote for your trustees. I feel very unsafe with that method. Coming from a local organisation that has trustees, and I am a trustee myself - we have a secret ballot, nobody knows who's voted for who. Because if you don't like somebody, if you're not putting your hand up to vote for somebody, you're voting for them en masse and I think it's just something you need to look at. We should have a way to reserve the right to have our say which also doesn't make us feel uncomfortable.

**Dave Webb:** "I represent the Bristol Mental Health Independent Network Group. I also have a problem with this. I don't think it should be about favouritism. I also think everyone should have a DBS check because we're working with vulnerable people... Many organisations have people they feel safe and comfortable with... We need to challenge this way of doing things."

**Sarah Yiannoullou:** We'll take on board all of those comments and we'll be looking at the selection process in the next couple of months and make sure we communicate that widely.

**ACTION:** Consider trustee selection and voting process/ expressing views methods. Review terms of reference.

**Nominations for honorary officers:**

**Co-chair** Dominic Makuvachuma

**Co-chair** Stephanie McKinley

**Co-vice chair** Sarah Carr

**Co-vice chair** Kathleen Lovell

**Treasurer** Mark Wood

**Dominic Makuvachuma: These are people that are already on the board and are positions that we're shifting around.**

- **Sarah Yiannoullou: This is for a one-year term.**
- **Alison Faulkner proposed the motion.**
- **Mish Loraine seconded the motion.**
- **Voting: Majority approved. No objections. No abstainers.**
- **Motion carried.**

# Item four & five

## Appointment of auditors and remuneration

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

**Q:** Cluny MacPherson asked to learn about the remuneration before the vote on re-election.

**A:** £1500 from Soka Kapundu, NSUN finance manager.

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

- **Cluny MacPherson proposed the motion**
- **Mish Loraine seconded the motion**
- **Majority in favour. None against. No abstainers.**
- **Motion carried.**

**The resolution put to the vote to agree the amount of auditors' remuneration for this year.**

**Cluny MacPherson proposed the motion.**

**Stephanie McKinley seconded the motion.**

**Majority in favour. None against. No abstainers.**

**Motion carried.**

# Item six

## Any other 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 box highlights



1. Kay Orme and Natalie Tucker, People in Mind (PIM)



**Kay Orme:** What we do is really important because when people come out from a mental health institution it's hard for them to come out into civilisation. Some of them shouldn't even have been discharged. That's where we come into it and we try to help as many people as we possibly can.

**Natalie Tucker:** People in Mind is more than a social group, it's a family. We all look out for each other.



2. Anjie Chhapi, NSUN volunteer and MAD Alliance member



We as members have big thinking caps, that's why we're here. We have big ears for listening to everyone's issues. We hear from each other because we give peer support. We've got big hearts for feeling, we have passion, that's why we're here. I'm here because of that. I'm really passionate about what happens in NSUN... We can take things forward nationally, locally, within our communities and groups. We have a big bag of tools. We have so much knowledge... I call myself an NSUN "PEST" – because I'm Passionate, Empowered, Survived for Today and Tomorrow.



3. Fiona Wright, Independent Mental Health Care consultant



NSUN has been described as being about lighting a fire under the issues and then throwing in an accelerant. I guess people like me – volunteers, activists and individuals – are trying our best to watch and tend to that fire with our voices and passions. Attitudes need to change at all levels - and my mental health and my physical health... can't and shouldn't be chosen between. We're here because mental health is important to us and I believe and hope it's possible that everyone else will catch up soon.



4. Vittoria De Meo, MAD Alliance member



Through my journey with NSUN I've had the privilege to revisit my life history through my personal narrative. Actually the visiting my past shaped and amended the perspectives of how I was perceived and how I may perceive myself. I understood along the way that my adversity was to become a driving force for my own victory. Every single individual has the capacity to overcome a difficulty, live a life of value, and influence positively the community at a local and global level.



5. Mish Loraine, Regional Co-ordinator at North East Together



We have worked with Mark Brown on a citizen journalism project which led to a book of service users' stories being published called Nothing Without us. We also run a newsgroup where our members create publicity material for the network such as flyers and newsletters, as well as maintaining our website, facebook page and twitter account.



6. Alison Faulkner, Independent Mental Health Care consultant



About the 4Pis: we've developed some flipchart-sized templates so that people can start to build up their own principles or purpose, presence, process. We're not going out there and telling people this is how you do involvement, we're saying let's do this together; it's more like a shared learning process than a training or a teaching exercise.



7. Nigel Moyes, NSUN volunteer



My story's entitled "Can you hear me, the voice of the service user" and I delivered this to over 400 people about a month ago, mainly university students, in Ipswich. I'm an ex-mental health service user and family carer. In summary I've been able to maintain my recovery through continuity of care, peer support, by developing my own resilience to trust people through improved confidence, the ability to say no and most importantly the strong relationship I have with my son.



8. Stephanie McKinley, NSUN trustee and Time to Change Manager at Mind



What we're really interested in now is sustainability, very much working with local communities about what we do to enable people to carry on the work after we go...It's really important that those of us who have lived experience are there at the centre, doing the work in the community, making those differences for all of us, and being what we would call a champion in everyday life.





## Soap box highlights



**9. Sohan Soraya Singh, NSUN member**

“

There's no accountability. There is no refining of the bill of Parliament. I've written to six prime ministers, I've written to the Queen, every authority in the land and I've had no reply, no result, no consequence. dd... 'There is no mental illness, there are physical symptoms caused by stress, overwork and other environmental and social conditions' and if you see the problem, you will see what's causing the problem, and then you will understand it. It's a shame, I think. People are subjugated.

”



**10. Kath Lovell, NSUN trustee and MD of Emergence**

“

I just wanted to pose a question really which is "How do we look after our leaders?" I really suffered last year, I took a bit of time out from work, I was very poorly. I wasn't helped at all by my local services but I felt that the support from my fellow leaders. There was a camaraderie about it, that we can do this and it's part of a symptom of the work that we do.

”



**11. Roland Urey, NSUN member and Mental Health Care Professional**

“

Remember my friends, life is fired at us point blank. The question is not to get cured but how to live. The challenge for us all at the dawn of the 21st century is the practical application and development of the concept of recovery. For a vision without action is a hallucination, isn't it? I haven't met a service user yet who wanted more genetic research! We need meaningful relationships and values. We are the experts in our objective experiences.

”



**12. Tas Iqbal, NSUN and MAD Alliance member**

“

I just want you to realise how many times when you're walking around do you see people in the street that you think could possibly be suffering from some sort of schizophrenia or some form of mental distress and they get picked up by the police. It happens. Being recruited by MAD Alliance... has been a life-saver because it's helping me to get myself together.

”



**13. Wendy Micklewright, NSUN member**

“

I adopt a similar approach to keep me sane which is I send out emails to our representatives because, when all's said and done, the NHS belongs to us, the politicians are accountable to us, so is the council and all those organisations belong to us. So we have a right to question them, to hold them to account and to ask for transparency. We can put our points of view across as Governors. I managed to achieve that with one of the local trusts that I'm with.

”



**14. Smiiffy, local mental health rap artist ([www.smiifyartist.com](http://www.smiifyartist.com))**

“

I started music to try and fit in because I was really unpopular. I'm not a mental health worker, I'm an advocate. That's why my music advocates for mental health. It's crazy how many people you can reach with music; now I've hit 22,000 people worldwide, so it's absolutely incredible. I love what I'm doing. I'm just trying to help more people and I believe we can all do that. I believe that even walking past someone in the street and smiling at them, ok they might not smile back but you've potentially saved someone's life.

”



**15. Musta, NSUN member**

“

I'd like to talk about positive energy – if you think good and do good, you feel good. If you want happiness for one hour, have a nap. If you want happiness for one day go fishing. If you want happiness for a year, have an inheritance from your parents. But if you want happiness for your whole life, do something meaningful to help others. In my life, I've been to the bottom, but I think you need to lose something to gain something. And now I'm an activist looking out for other people.

”



**16. Julia Smith, NSUN trustee**  
(Extract from Julias poem, first and last verses – read the full poem on line!)

“

The ten years since NSUN began have now flown

And in that time we can see how it's grown

From "Doing it For Ourselves" at the 2006 inception

We're together and other service providers collaboration

Together we're stronger, we're hard to ignore

And may it continue for another ten years or more!

”

NSUN AGM Evaluation summary

GENDER	
Male	15
Female	19
Transgender	1
Other	1
AGE	
18-25	0
26-35	4
36-45	5
46-55	14
56-65	8
66-75	6
75+	0
SEXUAL ORIENTATION	
Heterosexual	26
Bisexual	3
Lesbian	1
Gay	0
Other	0
REGION	
East of England	3
East Midlands	0
London	7
North East	4
North West	6
South East	2
South West	1
West Midlands	10
Yorkshire & Humber	3
Wales	1
ETHNICITIES:	
Asian/Asian British – Indian	2
Black British – African Caribbean	2
Black British	1
White British/English/Welsh/Scottish/Northern Irish/British Irish	28
White Other	3

**Key points**  
From the 100 people who attended 39 people completed the evaluation form.

- **Purpose:** the purpose of the event was clear
- **Participation:** those attending felt able to participate
- **New information:** they learnt new information.

The majority of the 39 who replied also agreed (or strongly agreed) that they:

- had made **new contacts** (37:39)
- felt **more connected** to the NSUN network as a result of the event (37:39)
- felt **more prepared** to get involved to influence others (36:39, with 28 agreeing strongly with the statement)
- felt they had **received support** from peers (38:39)
- felt they had **provided support** to peers (35:39)
- felt they had **been listened** to and their opinion valued (36:39).

It was really helpful listening to other people's views.

Meeting like minded, like spirited, and not so like minded people. I feel both challenged and supported.

What did you find most helpful about this event?  
A selection of comments are included here:

It was clear that **networking** and **connecting** with others, **meeting new people** was the most important thing for many, with 11 people making comments, for example: "Reconnecting, hearing others, getting involved in the passion and opinions."

**Listening to people's experiences** and views generally was also commented on: "Meeting like minded spirited and not so like minded people. I feel both challenged and supported."

**Soap boxes** were well liked: "I enjoyed all the wonderful testimonies of people's lives. Soapbox slot was great – great idea - 4 minutes was enough to get a good flavour of diverse messages, personalities and positions."

**Afternoon session – panel discussion:** was described as "good stuff.

And music, fun. Enjoyed Smiffy."

**Location/venue:** "...the location of the venue – Midlands based – bringing everyone together.

**Other positives:** visual aids (Debbie), meeting staff and trustees, inspiration, clarity, vision and a host of positive comments, for example, "first rate," "great event," "...all of it." Some people said that they "would like to get more involved," that it was "a really informative day" and that "people's survival journeys to wellness were inspiring."

The life experiences were amazing. People's survival journeys to wellness were inspiring.

What did you find least helpful about this event?

**AGM business** was seen as boring and presented a challenge and to some: "AGM needs fine tuning."

**Content of the afternoon session** was too political or complex for some: " too controversial. Too militant"... "the quantity of new knowledge was quite tiring." ●

We would like to thank our supporters who have have recognised that we are doing a valuable job for our members and the wider community and that we are worth funding for the future.



## Shaping Our Lives



### Launch of 'From Mental Illness Towards a Social Model of Madness and Distress' 8th June 2016

#### Introduction

To celebrate the launch of the report 'From Mental Illness to a Social Model of Madness and Distress' a panel discussion was held at BVSC, the Centre for Voluntary Action, on the afternoon of 8th June 2016 following the Annual General Meeting of NSUN. Around 90 people who use mental health services and/or have an interest in mental health attended a group discussion hosted by an expert panel.

**Panel members: Peter Beresford, Mary Nettle, Brigit McWade, Alison Faulkner, Dominic Makuvachuma, Sarah Yiannoullou (Chair)**

**Peter Beresford** started the discussion by announcing the launch of this user-controlled research. He summarised the findings as follows:

Firstly, the report concluded that professionals and the general public interpret mental distress as a medical issue through the medical model, seeing a problem



in the individual. Many people end up internalising that model, which evidence suggests is inherently damaging and stigmatising, putting an additional emphasis on medication as the treatment.

Secondly, the medical model tends to be poor in addressing issues around ethnic differences and cultural differences, and can often be experienced as punitive to people from ethnic minority communities.

People also felt that a more social understanding of distress was needed, looking at the whole person, in their particular environment and circumstances. People felt that a holistic approach recognises 'that which is human' and individuals are perceived as unique individuals.

Finally, while many see the recovery model as a great idea and a good way forward, others feel policy has pulled it away from its original user-led ideas, and that it now perpetuates a medical approach. It puts more responsibility on the individual, who has to bear 'the cuts' and it has become unhelpful. Peter suggested that personalisation has become marketisation - subverting and diverting user controlled services.



In summary, although the social model of disability was introduced by the Disabled People's Movement, there are mixed feelings about seeing mental distress as an impairment. Some people do think it's helpful to have close links with the disabled people's movement but not necessarily to identify as disabled. Language is also important: not everyone is comfortable with the use of the word 'Madness', and reclaiming that word, as it is still stigmatising in a stigmatic world.

Questions and comments to the introduction from the audience included: protection that mental health survivors and service users get under disability law; and whether mental health/distress should be viewed as a separate characteristic. This was followed by acknowledgement that access to services and support, such as travel passes, are not afforded to people with mental health needs who do not fit the disability criteria.

Peter's views were echoed by a member of the audience:

"great initiatives and good ideas from the service user movement get contorted or distorted, and are seen through a different lens, such as personalisation becomes



marketisation, and recovery becomes you're fit for work. How can we avoid our good ideas being twisted against us and or co-opted in such a way?"

Peter responded by talking about the importance of collective strength and solidarity in protecting our ideas.

#### Panel discussion

Each member of the panel was then invited to make a comment relevant to the findings of the report.

**Mary Nettle** (a veteran survivor activist) agreed that ideas do get hijacked. She also agreed that survivors and service users don't have the same rights as disabled people. She has worked with the European Network of Survivors of Psychiatry (ENUSP) and the World Health Organisation (WHO) making sure that the psychosocial model was reflected in an important piece of legislation, the United Nations Convention for the Rights of Persons with Disabilities (UNCPRD). There is a great deal of work in the European Union (EU) and the Parliament about disability, that many people know nothing about, which is tragic.

**Brigit McWade** (a sociologist who studies madness and distress and



Mad Studies) congratulated Peter and the other authors for this work, and stressed its importance in highlighting complicity and diversity. Brigit asked, "What are we pointing to when we say medical model - a serious lack of choice? Is it: take these pills and go away or if you're not here we can't help you?" The other end of that is forced treatment and coercion; that is not to say that the medical system is ubiquitously unhelpful, but that the way in which it is practiced, and the options available, need serious questioning. What the report says about recovery is supported by Brigit's own research into how mental health services have tried to put recovery into practise and there is no single definition. Brigit also talked about discriminatory policy implementation, and a system that fails some people more than others, alongside the culture of blame around welfare reform. It is important to see the views of people from black and minority ethnic communities in the report, especially at a time when the over-representation in detentions for this population continues to be reported. Brigit asked some questions about the law and the criminal justice system and what/how a focus on the medical model might divert our attention from



this? Also asking, can we create something that isn't either social or medical but instead embraces new forms of knowledge? And finally quoting Jasna Russo: "We have to unlearn what we know in order to create new knowledge but holding open that space is difficult".

**Alison Faulkner** (Survivor Researcher and Journalist) reflected that the report reminded her of just how early you could get your distress interpreted in a medical way. She shared some of her personal experiences of how the medical model seemed to perpetuate itself through prescribing and interventions that did not address her individual needs. Alison felt that medication did not help specific experiences but deadened the feelings the experiences evoked, and she wanted to see less research into psychiatric drugs. As a survivor researcher, Alison felt that the medical model has profound implications of what is researched and, like Peter, challenged that research paradigm. The co-option of peer support and recovery meant that the current paradigm is seeing peer support as a clinical intervention with an outcome, such as how it might prevent you going into hospital. Alison admitted to being somewhat pessimistic about how we could change or turn this



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around and wanted to hear from others on how to move forward.

**Dominic Makuvachuma** (NSUN Co-chair and survivor activist) started by saying that his frame of reference was written by his life experiences - coming from Zimbabwe, growing up in an Apartheid system, and not being treated as an equal. After moving to the UK and experiencing a racially motivated arson attack he has spent his life challenging inequality issues. Dominic felt that 'Recovery' implies that there is recovery from some kind of ill health. He ran away from that notion, and was non-compliant, and consequently given all sorts of psychiatric labels. When thinking about 'recovery' Dominic said that for him there was a 'dis' missing as recovery is about rediscovery and reconnecting with yourself and your community.

**Dominic** wanted to see people take more of an interest in what black and minority ethnic (BME) groups are doing as they seldom get the chance to be fairly represented - 'on our own terms'. It was important to work collectively, enabling other forms of participation and communication than just the written word - we all work differently with issues and agendas.

**Sarah** asked if Peter and Mary could respond to Brigit's question about criminal justice, and also what might the medical model divert our attention from.

**Peter** talked about the mental health debate at the Old Vic and the discussion about how mental health was not keeping pace with other policy areas. It was a polarised discussion with Luciana Berger MP, Paul Farmer CEO of Mind and the President of the Royal College

of Psychiatrists, Professor Simon Wessely. Surprisingly it was Luciana Berger who was closer to our views than the others. Also present were two powerful groups, the Mental Health Resistance Network (MHRN) and Disabled People Against the Cuts (DPAC) who were given short shrift by those who were very clearly embedded in the biomedical model. People were (rightly) getting angry and had to leave. Peter felt that some major organisations were still getting massive resources to 'go with it' when the greatest source of discrimination is coming from the government that is funding anti-stigma campaigns such as Time to Change.

**Mary** said that the research did not ask any questions about criminal justice and it wasn't raised as an issue with anyone involved in the study. Although controversial, Mary felt that secure units such as Broadmoor and Ashworth should be closed, and prisons should be able to deal with everybody who has committed an offence. People should be treated in prison but not just with pills. Mary also cited the UNCRPD Article 12: Equal recognition before the law that states that we should be able to say no to treatment. When challenged, the Government says that you are not a disabled person; these double standards are shocking.

The discussion was then opened up to the audience. Responses from the floor included an activist from Hear Our Voice in Wolverhampton, who talked about the difficulties you encounter when the group or 'the voice' gets louder - funding seems to disappear and you get shut down. This can mean that activists revert to working alone, and it can be harder to be properly informed.

**Sarah** said this related to one of the recommendations in the report about sharing and making allegiances and also asked how social approaches to mental health could be taken forward, inviting further comments from the audience.

Another attendee spoke about the concept of recovery: "It is not possible to recover from your sexual orientation or from being Zimbabwean, Hungarian etc. It is a conceptual mistake to have 'recovery' from something from which recovery is not possible".

He also said that he did not see the neurological diversity, and the spectrum on which he moves around, as a disability but as an expression of the human condition. "From a class based perspective only the privileged are frightened of losing their position, the middle class are frightened of being working class, and working class people then look at the most different and disadvantaged and think I don't want to be like them. It is an injustice that some are treated so unjustly, segregated and treated harshly. There needs to be a united convention for people with neurological, diverse expression".

An attendee suggested that the survivor user movement can sometimes take a victim position, and it is difficult to mobilise and campaign if people sound like victims. "We have to become a resistance movement, and maybe go underground, or it might come down more harshly on us".

The panel was asked why they think power hasn't been transferred to us and, if we did get it, what would we do with it?

Another member spoke about her optimism and belief that we are



stronger together. She said she was sad when Alison expressed she was losing trust and was pessimistic. As a positive psychology campaigner she has learnt through experience that when life is hard it teaches us to accept different psychological states. "We must be aware of positive psychology from an early age. If we do not understand and accept it we will never get out of it. We are in a world where everyone is in a rush and the options are limited".

Another person said she had given mental health a lot of thought, especially her own experience of being distressed, as she works with psychologists who she doesn't always agree with. In relation to the question about the Medical Model, she is not a fan, but accepts that there are people who will be defensive about it. "It is a framework that helps professionals take us seriously, so it is important that we consider all packages". She also spoke about the lack of reliable evidence around some diagnoses, saying that she felt tricked when

she was informed that there is no such thing as bipolar, and that this is unethical.

### The panel responded to these comments as follows:

Firstly, **Alison** explained that she was pessimistic about changing and challenging the medical model; she hadn't lost trust and generally felt she was a positive person.

**Dominic** considered the question about why power is not transferred and what would we do with it if we got it? He talked about growing up with parents saying he could do or be whatever he wanted to be, even living within the apartheid system. He was brought up fighting for his rights (although not always knowing exactly what he was fighting for) and that he never felt powerless. In later years he felt a similar spirit in the survivor movement - not always understanding what people were talking about, not always knowing what you were fighting for.

A comment was made: "Now we're much more visible at NSUN,

and vulnerable. Maybe we can be chopped down and pruned to size by those who have the power (the money)".

However, **Dominic** questioned this, saying that we've got to stay with the power within, and we need to make that collective, as it can't be suppressed forever.

**Peter** said he was very taken by comments made by the last two women. These were very different times which could be seen as both encouraging and worrying. That said, he felt coming together as we had today would not have been possible 30 years ago, and it is symbolic of many more people getting together as survivors. Survivors are writing books, making programmes and communicating creatively.

**Peter** mentioned his recently published book 'All Our Welfare' which tries to make sense of the welfare state and asks how should people look after each other in the 21st century? Jasmine Brown



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writes in the foreword: “since when did how we look after one another become contentious?” Peter said “she has put her finger on the point, as everything seems to be about how we should not look after each other. There are so many attacks and cuts, and then the staying or leaving the EU being framed in terms of hatred: hating people, hating immigrants which is shocking”.

**Peter** said that while politicians don’t go about physically bashing people, other people will be going about bashing people based on what the politicians say.

**Mary** felt she was able to shout loudly about other people’s rights having been in mental health services since 1978. She said that she had just been discharged from secondary mental health services back to her GP, much against her will. After years of services supporting and enabling her, she is now left cross, helpless and voiceless. There is no self-referral process back into the service if needed. Mary said she recognised that she has herself bought into the medical model after being in the system for so long, but felt strongly that we have a psychosocial model that protects our rights.

**Brigit** responded to the comment about the medical model and its power to make you be taken seriously. She felt that this could be seen in the Mind Anti-stigma campaign which suggests that mental illness is an illness like any other, but it is stuck in the history of psychiatry, a branch of medicine that has never been taken seriously itself. Psychiatrists have their own anti-stigma campaigns, saying: “poor us, nobody takes us seriously”. Brigit said that she was aware of current academic views

that psychiatry is totally irrelevant and out of date. The landscape in medical research is shifting into neurological science in a troubling way, so when you do get taken seriously, alarm bells should be ringing. However, she could see that we might want to tap into that ‘power’.’ She went on to talk about the power of resistance, and knowing that you are being listened to, and that when you get abuse it is because you have upset people.

An audience member spoke about the Staffordshire user led revision of recovery based services, with 50% of the panel having a diagnosable mental health issue. Asking: is this the future, are we going to take over the asylum and is this a good thing?

**A member** from Bristol was concerned about large organisations creating conflict, and setting users against each other applying for bids, commenting that people at the top don’t want to lose their power.

**Sarah and Debbie were asked what the key message from the event would be.**

**Debbie** said it would be about power, and how you can change things despite thinking you have just a little power. Also the importance of passing on power and knowledge.

**Sarah** said, following the Soap Boxes, it would be confidence in yourself and the importance of knowing your rights. “That is power, individually and together knowing our rights, and setting our trajectory to use those rights”.

She concluded by saying it was important to know what to challenge, when there is so much, and invited final comments from the panel.

**Dominic** used the analogy of a

broken windscreen when the whole car needs redesigning – let’s not just fix the windscreen.

**Alison** said she used to say that there is absolutely nothing we can do about it, as we need to completely close all the Acute Units. Now we need to take our discussions about social approaches to higher places and really make change happen.

**Brigit** said it was about resource allocation and that she had picked up a strong desire for change in the room. She also heard talk about things that have happened to us that shouldn’t be medicalised, and recovery in the context of decreasing funding that make us feel precarious. The other big issue is welfare reform, and a feeling of being attacked from every direction. Brigit therefore declared that collectivism is what she was pinning her colours to.

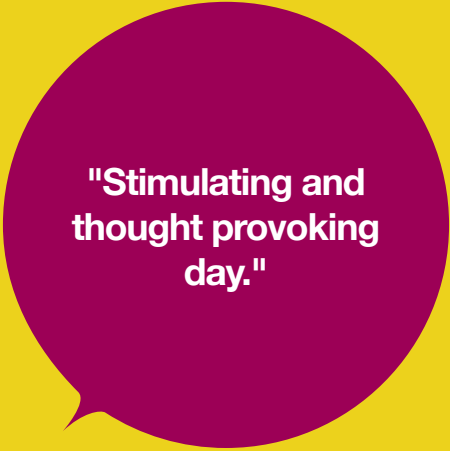
**Mary** said it had been a privilege to work with Peter, and that she would now like to see a project based on the UN convention and the psychosocial approach, educating and informing people about it.

**Peter** thanked the panel members and the researchers and everyone who made the debate such a lively and thought provoking one. He said he understood Alison saying earlier that she was pessimistic as we are in terrible reactionary times, but what was great was what was happening amongst us. Peter urged all to hold on to the confidence that has got us to where we are now, using the saying ‘and whoever said life was fair’ - we are the ones that are going to make it fairer. ●

*More photos available here <https://www.flickr.com/photos/89305593@N02/albums/72157669333061322>*

# together we are stronger





**"Stimulating and  
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