

annual report 2018-2019

We are here to make sure the voice of experience is heard



The National Survivor User Network (NSUN) is an independent user-led network, bringing individuals and groups together to communicate, support each other, share experiences and have a voice. Crucially NSUN is a membership network led by people with the lived experience of distress or diagnosed mental health issues. It is a growing network with the strength to challenge inequality and improve lives.

National Survivor User Network PO BOX 74752 Lond

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Charity number:

1135980

Company number:

07166851

OUR VISION

Our vision is for the lives of people who experience mental distress, discrimination and disadvantage to be better.

OUR MISSION

Our mission is to create a diverse, inclusive and influential user-led network with the strength to challenge inequality and improve lives.

OUR AIMS

- To create and strengthen links between individuals and groups.
- To support and promote user-led groups and initiatives.
- To influence and inform policy and decision makers.

OUR VALUES

- **Solidarity** our network recognises commonality of interests and experiences, and facilitates mutual support.
- Equality we believe all members should have equality of status, rights or opportunities.
- Integrity we strive to express the views and experiences of our members in an unbiased and unfiltered way.
- Diversity we understand, recognise and value difference - our different backgrounds, experiences, ethnicities, beliefs and abilities.





Managing Director, Sarah Yiannoullou

March 2019 marked my tenth year in post as Managing Director. Over the years, I've met and worked with so many inspirational people that have provided support, guidance and direction. The resilience and passion of our membership has created a powerful collective that has been the foundation of the growing network. It's been our ambition to reflect and respond to the diverse experiences, views and ideas of our members in a way that makes them feel that we are doing something that's making a difference.

At the beginning of 2019, we launched our main campaign, the 'Value of User-led Groups', to raise awareness of the shocking amount of user-led groups and organisations disappearing and to fight the cause for their survival. This will continue in to 2020.

In April 2019, we had to make some reductions to the core team and formally introduced the Associates model. Although the restructuring was a necessity due to funding it also provided an opportunity to take stock and make changes following our Development Project.

Over the course of 2018-2019 we took a close look at what we've done over the last 10 years and what we need to do in the future. So much has changed since NSUN came into existence so it was important that we considered how we might change and do things differently.

NSUN will continue to facilitate autonomous action by framing our work in the following way:

• Past: our personal stories and

- narratives our history, reparative justice, understanding and communicating how we got here.
- Present: our lives now, setting our own agendas, developing our own projects, conducting our own research, communicating the present condition of people, influencing events as they unfold, engaging with the existing landscape to make it work better for people.
- Future: our influence on future policy, shaping debate, supporting people to find their place, working on long term plans and ideas to make significant and lasting change.

There is no other organisation that has taken on the responsibility of protecting and promoting our forgotten and ignored stories of the past, present and future.

The Members' Manifesto has been guiding our work since 2015 and has been reviewed and refreshed every two years. The 2019 version will inform our priorities for 2020 over the next two years.

2020 will be an exciting time for NSUN as we welcome new operational leadership and trustees. During this time of change, the transition and succession management process will be well supported and considered to make sure the network has the best possible chance of continuing for the next 10 years and beyond.

Sustaining and strengthening our collective political voice is all the more important now than ever.

Thank you to all – it's been emotional! ●

MEMBERS MANIFESTO

We aim to:

- Campaign against the injustice and harm caused by cuts to public funding and welfare benefits.
- Challenge the abuse and coercion that continues under mental health legislation and work to ensure that people understand and can enforce their rights under the UNCRPD.
- 3. Actively promote the need for genuine partnership with us in strategic and commissioning decisions and in service provision and the need for user-led provision as well.
- 4. Challenge personal, institutional and structural inequalities, injustices, disadvantages and discrimination for everyone with experience of mental distress/trauma.
- Promote informed choice so that people are in a position to understand their difficulties in whatever way they choose and to access the support that they find best.
- 6. Promote the validity of survivor knowledge and research. ●

A message of hope





Chair, Mark Wood

This last year for NSUN has been one of transformation, stabilisation and transition.

Transformation

The plans laid down to reorganise NSUN into a smaller core with additional Associates, employed as and when required, were put into effect in 2018/19. The trigger for this may have been decreasing resources but I believe that the new structure gives us an organisation that can be reactive to opportunities as they arise but also proactive in amplifying the voices of the user-led movement.

Stabilisation

Due in no small part to the transformation in our structure along with our long-term vision, we were able to attract three years of vital core funding from Esmée Fairburn and Tudor Trust. Thanks to those two charitable trusts we have the basis of a future.

Transition

The breathing space offered by the core funding gives us the opportunity to work on diversifying our income so that we avoid being caught up in a cycle of scarce resources and becoming more influential in speaking truth to power.

Part of our period of transition will be, for many of us, bittersweet. The bedrock of NSUN and, as I've seen it, its beating heart, Sarah Yiannoullou will be standing down as CEO and passing on the baton to her successor. Throughout my six years involvement with NSUN as a trustee she has been a tower of strength and provider of much sage advice. As I write, that successor has vet to be appointed. I hope we are able to share the news of that appointment at our AGM and members' event in York. Whoever we appoint. I know that Sarah and I will be supporting that person into the role. Those will certainly be some big shoes to step into.

The Independent Review of the Mental Health Act

Mental Health Alliance survey as a main source of evidence due to reservations of its reach and recommendations. Meetings were held with the Review secretariat lead, Richard Kelly to influence wider involvement of service users and user-led groups. NSUN led a workshop with DHSC team with survivor researchers to inform topic guides for the service-user and carer focus groups. NSUN was successful in bidding to run five focus groups over the two consultation phases and also organised a coalition of user-led groups to gather feedback and inform a letter of concern to the Chair and Vice-chairs, followed by a meeting and further letter. Guidance was produced for members to contact their local MPs to lobby for a 'rights based' Mental Health Act. We produced accessible briefings and updates of the final Mental Health Act Review report and a variety of comment pieces, and we presented at events.

DHSC were made fully aware of the difference between user-led and non-user-led groups. Survivor/user-led research was considered in the review process. Evidence was gathered from NSUN members to feed into topic group evidence and call from UN Rapporteur. Letters (with signatories) sent to Review Chairs and politicians leading to increased awareness of the UK UNCRPD recommendations.

Our people



Our team

Sarah Yiannoullou Managing Director

Zoe Kirby

Admin and Membership Manager

Dr Emma Ormerod Research Manager

Stephanie Taylor-King

Communications Co-ordinator

Soka Kapundu Finance Manager

Our trustees

Trustees who served the charity during the period were as follows:

Mark Wood - Chair

Helen Oldfield – Treasurer (Co-opted October 2018)

Alisdair Cameron

Julia Smith

Joe Kelly

Eleni Chambers

Sarah Carr

(Resigned January 2019)

Dominique Makuvachuma (Resigned October 2019)

Stanbania McKinlay

Stephanie McKinley (Resigned April 2018)

Daisy Abraham

(Resigned September 2018)

Henderson Goring

(Resigned October 2018)

Nic Murray

(Co-opted October 2018)

Rachel Rowan Olive

(Co-opted October 2018)

Dawn Willis

(Co-opted October 2018)



Our associates

Mark Brown, Alison Faulkner, Naomi Good, Raza Griffiths, Stephen Jeffreys, Jayasree Kalathil, Colin King, Helen Lang, Mish Loraine, Nash Momori, Dina Poursanidou, Debbie Roberts, Phil Ruthen, Kirk Teasdale, Premila Trivedi

Our Governance

The board is responsible for the governance and strategy of NSUN and is elected by the members. The trustees bring a mix of skills, experience and qualifications. All trustees have lived experience of mental health distress and/or service use and are mental health activists. Members are normally appointed for a renewable term of three years.

The Board meets six times a year and delegates day-to-day responsibility for the running of NSUN to the operational team. See the Scheme of Delegation.

The subcommittees meet to look at finance, fundraising and human resources in more detail in between Board meetings.

As a charitable company, NSUN's governing document is its <u>Articles of Association</u>. A fair and open recruitment process has been developed to ensure that the Board reflects both the user-led ethos of NSUN and the diversity of the wider network. Following an application and interview process, successful applicants are proposed to the membership at the annual general meeting.

Our history



- The network was set up to build a more united and confident mental health service-user movement. It recognises the isolation, discrimination and disadvantage experienced by mental health service-users and their needs beyond clinical treatment.
 - 2003 On Our Own Terms report makes a recommendation to form a national service-user/ survivor network
 - 2006 The 'Doing It For Ourselves' conference launches the idea of a national network and a steering group is set up to make it happen
 - **2007** NSUN is launched after securing funding for five years
 - **2008** NSUN is hosted by Together for Mental Wellbeing and shares accommodation with Catch-a-Fiva
 - **2010** NSUN becomes an independent organisation
 - **2011** NSUN holds its first annual general meeting
 - **2012** NSUN secures a further three years' funding
 - **2013** NSUN attracts over 2000 members
 - 2014 NSUN hosts the IIMHL Service User Leadership and Peer Support festival
 - **2015** The 4Pi National Involvement Standards are published and launched
 - **2016** The #NSUNthrive10 campaign is launched
 - **2017** NSUN increases membership to over 4500
 - **2018** NSUN launches the Reigniting the Space (for BME user/survivor voice) Project
 - **2019** NSUN launches the 'Value of User-led Groups' campaign.

In 2003, service-user-led research, coordinated by Jan Wallcraft for the User Survey Steering Group and funded by the Sainsbury Centre for Mental Health, resulted in the report 'On Our Own Terms'. It urged the formation of a national network to bring individual mental health service users and groups together to encourage good practice and build the capacity of the sector. Inspired by this report, the Sainsbury Centre funded a number of meetings and a conference in London in 2005 to agree on some practical actions based on the recommendations.

A steering group organised a conference focused on how to set up a national service-user/survivor network. Nearly 200 service users and survivors attended the "Doing It For Ourselves" conference in Birmingham in March 2006. The national planning group that grew out of the conference included representatives from a whole range of service-user and survivor-led groups.

Funding for five years was obtained from Comic Relief and the Tudor Trust and a hosting arrangement was negotiated with the mental health charity Together: Working for Wellbeing. NSUN received invaluable support with financial procedures and human resources but remained selfgoverning throughout the initial three years. The national planning group was then dissolved and replaced by a management committee, selected by an independent panel of service users and survivors.

A launch conference was held November 2007 in Poole, Dorset (see video of the event Service User Conference on the NSUN YouTube channel).

NSUN became an independent charitable company May 2010 •



Reigniting the Space (for BME user/survivor voice) Project

A group of BME user/survivors, including some of the original steering group members of Catch-a-Fiya, have been working in collaboration with NSUN to recreate a national platform. The Lankelly Chase Foundation funded this work. The project started with mapping the current work mental health service users and survivors from racialised groups are involved in around the country. Through this process,

- Make available a clear picture of the current work and activities undertaken by BME mental health service users and survivors and their groups in addressing multiple and intersecting disadvantages.
- Identity specific needs for capacity building and infrastructure for national collaboration and mutual support.
- Document the work led by BME user/survivors, acknowledging achievements and sharing ways of working.
- Document theories and practices of user activism and involvement in mental health which truly reflect the diversity of viewpoints and ways of working.

Our strategic aims



As a membership network we are constantly listening to, responding to and being informed by what our members says. Our work is informed by the Members' Manifesto and organised into an operating plan with ambitions under the following strategic aims:

Membership

- Increase membership by 20% each year, to include both individual and organisational membership
- Improve membership communications
- Ensure members are at the fore of campaigning
- Increase local and regional presence and support the development of strong hubs across the regions.
- Develop and manage relationships with individual members, directly reach more marginalised communities
- Develop membership pack

Communications

- Ensure messages and presentation of information is consistent and responsive to the views and wishes expressed by members
- Facilitate and support communications between members and communities
- Increase presence and profile in local and national media
- Develop systems and profile on social media

Research

- Promote and develop serviceuser/survivor-led research and knowledge production
- Develop and sustain the Survivor Researcher Network (SRN)
- Conduct membership polls and quarterly feedback cycles to canvas member views
- Facilitate collective policy responses
- Develop a repository of survivor

- researcher produced knowledge
- Continue to seek new partnerships for research funding proposals

Capacity building & technical assistance

- Support user-led groups/initiatives in local areas.
- Facilitate and support local/ regional networking.
- Deliver training and workshops
- Visit member groups for exchange of ideas
- Provide hosting arrangements for user-led groups and initiatives

Involvement & influencing

- Ensure that there is a strong user voice, at an individual, community, organisational and strategic level through the promotion and implementation of 4Pi involvement standards
- Support people to lead the agenda rather than respond to it
- Campaign for the authentic, independent and direct voice
- Review and update the Members' Manifesto annually

Sustainability and independence

- Diversify core resources and continue to grow our unrestricted income each year
- Make best use of available mentoring and management support
- Apply to Charitable Trust funding for core activity
- Manage our growth within the means of our resources
- Develop business proposition of 4Pi and SRN
- Develop partnerships with organisations that reflect our values
- Attract donor funding
- Introduce membership charging for Allies and non-user-led organisations
- Hosting of user-led initiatives and projects



Survivor Researcher Network

The SRN working group continues to meet to progress the ambitions set out in the SRN Manifesto 'Mental Health Knowledge Built by Service Users and Survivors'. In addition to facilitating focus groups for the first and second stage of the Mental Health Act Review consultation phase, members have presented at various events. SRN also signed an open letter to Lancet Psychiatry December 2018 and represents NSUN at the Alliance of Mental Health Funders meetings.

4Pi National Involvement Standards

The 4Pi National Involvement
Standards is a framework for
involvement and engagement
that evolved out of decades
of 'activist' experience and
the themes of equalising
power, recognising diversity
and commitment to genuine
change. It is now recognised
and used nationally and
internationally in practice
and policy and has been
referenced in the Five Year View
for Mental Health and CQC's
Mental Health Act report. Our
Associates have continued to
deliver training and guidance
to organisations that are using
the framework to develop their
policies and practice.

Summary of our work and achievements



Key Successes 2018/2019:

- Providing a publishing platform for member blogs and articles
- Weekly ebulletins sent to members providing information on NSUN work, membership news and events, opportunities and consultations, and policy updates.
- Continuing to add photo records of activity to the <u>NSUN Flickr library</u> and publishing Member Soap Boxes and three NSUN films on the <u>NSUN YouTube</u> Channel
- Launching the new <u>NSUN website</u>, CMS and membership database 2018
- Hosting and co-ordination of the Survivor Research Network (SRN) with over 300 members and a core working group; launching the SRN Manifesto 'Mental health knowledge built by service users and survivors' for lobbying purposes; named as partners in seven national research and policy projects with academic partners (Middlesex University, University of Warwick, University of Birmingham, Birmingham City University, University of Essex, St George's University of London, University College London)
- Launching the user-produced Kindred Minds BME Manifesto 'A Call for Social Justice'
- Chairing the Principled Ways of Working conference and leading the production of the <u>Principles</u> of <u>Peer Support Charter</u>, bringing together 12 voluntary sector and Sussex NHS Partnership NHS Foundation Trust organisations across Sussex to promote, protect and map peer-led peer support
- Increasing sign-up and use of the

- 4Pi National Involvement Standards by voluntary and statutory sector organisations, locally, nationally and internationally
- The annual member event in Derby October 2018 <u>exploring the future of peer support</u>
- Successfully lobbying for increased involvement of people with lived experience in the Independent Review of the Mental Health Act
- Member of the Independent Mental Health Act Review Advisory Panel and Topic Group Addressing Rising Detention Rates
- Facilitating three service-user focus groups for the Independent Mental Health Act Review
- Facilitating focus groups and input in to the Women's Mental Health Taskforce and report ensuring the voice of experience was adequately included
- Being a member of two partnerships (the user-led Win-Win Alliance and the Mental Health Consortia) in the Department of Health and Social Care Health and Wellbeing Alliance (HWA)
- Facilitating a 'Deep Democracy' event for the HWA Alliance Disability and Employment projects
- Working with and supporting over 2,000 individuals though training, events, peer support, providing information, strategic advocacy and signposting
- Reviewing the <u>Members' Manifesto</u> 'Our Voice, Our Vision, Our Values'
- Member of the Five Year Forward View for Mental Health Oversight and Advisory Board – feeding in to the development of the Commissioning Assessment Framework (CAF) and lobbying for improved involvement and co-



Health & Wellbeing Alliance

The HWA is jointly managed by the Department of Health and Social Care (DHSC), Public Health England (PHE), and NHS England and is made up of 21 voluntary and community sector organisations. NSUN is a member of two HWA partnerships, the Win-Win Alliance (Shaping Our Lives, Disability Rights UK, Change) and the Mental Health Consortia (Association of Mental Health Providers, Centre for Mental Health, Mental Health Foundation, Mind, Rethink). We produced briefings on 'Suicide Prevention' and 'Peer Support and Prevention' and delivered a webinar to introduce the briefings.

Principles of Peer Support

Our work on protecting and promoting the core principles of peer support continues through the hosting of the Peer2Peer Network, facilitating special interest groups such as the Involvement Workers Group, and leading a partnership between voluntary sector organisations and Sussex Partnership NHS Trust to continue to promote the Peer Support Charter and map peer support in the community.

Summary of our work and achievements



- production in the work.
- Co-chairing the Metropolitan Police Service Mental Health Consultative Group and recruitment of service-user representatives members to a group that previously had no 'lived experience' involvement
- Working in partnership with three national alliances on joint campaigns (NICE guidance on Recognition and Management of Depression in Adults is not fit for purpose, Social Workers and Service Users Against Austerity, Mental Health Act review user group coalition)
- Facilitating peer support groups (Involvement Workers Peer Support Group, Redcar rural peer support group, Peer2Peer network)
- Member of Mind's <u>PeerFest</u> planning group informing and shaping the tender rounds and events
- Member of the Every Mind Matters Content Delivery Group

We continued to facilitate and support people to lead their own projects and campaigns, to lobby for their rights and to be more involved in their care, in their own community, and where appropriate and relevant, wider policy initiatives to influence change

NSUN has hosting arrangements for:

- Real Insight
- North East Together
- Kindred Minds BME Manifesto project
- Peer2Peer

We will endeavour to secure core funding that enables us to plan and support user-led projects and respond to unplanned opportunities and initiatives

Campaigns 2018/2019:

NICE campaign: A coalition of organisations produced a briefing in response to the draft guidelines on the Recognition and Management of Depression voicing concerns about significant flaws in methodology, lack of transparency and inconsistencies in the document

Global Ministerial Mental Health
Summit: NSUN led on a letter
raising concerns about the way in
which this event was organised and
about the UK positioning itself as
a 'global leader' in mental health.
194 signatories were gathered
worldwide. NSUN was also a
signatory raising similar concerns
but with a focus on involvement-led
by Peter Beresford

The Value of User-led Groups:
NSUN worked with Shaping Our
Lives and People First to raise
awareness of the dramatic loss
of user-led groups over the last
few years from their respective
networks. After approaching
Lankelly Chase, an event in May
2019 brought together user-led
groups with funders to discuss the
issues contributing to the demise
and looking at what collective action
could be taken. Read more here

Videos produced 2018/2019

NSUN in 2018
Principles of Peer Support



Regional Networking

NSUN has supported the development and hosting of the North East together (Net) service-user and carer network Joint work has resulted in a number of events and focus groups that have directly fed into policy consultations and developments at a local and national level.

London networking has strengthened through a number of projects such as the Healthy Lives user-led study, looking at 'improving physical health services for people diagnosed with serious mental illnesses', the Healthy London Partnership

Crisis Care Programme and facilitation of the service-user and carer advisory group and the London Leadership programme.



INCOMING RESOURCES GENERATED FUNDS:	
Investment & Other Income	£50,536
INCOMING RESOURCES FROM CHA ACTIVITIES:	RITABLE
Grants	
Trust for London	£20,000
Tudor Trust	£30,000
Lankelly Chase	£30,000
Lankelly Chase (Hosted)	£41,265
Health & Wellbeing Alliance	£13,125
Mind	£30,000
TOTAL INCOMING RESOURCES	£214,926

EXPENDITURE FOR 2018-2019	
Staff costs	£116,774
Projects	£33,800
Strategic Advocacy	£53,961
Regional Development	£6,351
Members' event	£7,989
Staff/Project expenses	£11,782
Office expenses	£7,527
IT, Media & Website	£15,874
Governance	£3,634
Depreciation	£508
TOTAL EXPENDITURE	£258,200

The main source of funding for NSUN during 2018-19 remained grants received from charitable trust foundations as detailed on page 9 of the Annual Audited Accounts for the year ended 31 March 2019. NSUN's trading income saw a reduction of 55%, from £92,143 (2018) to £50,536 (2019).

Income

Income during the period 2018/19 was £214,926. This is a 21% reduction in income compared to 2017/18 (£273,301). Seventy-six percent of the income during 2018-19 was restricted funding, that is funding restricted to support specific work.

Expenditure

Expenditure during the period 2018/19 was £258,200 (2017/18 £263,805), a decrease of 2%. All expenditure, with the exception

of governance costs, was spent directly on NSUN's charitable activities. Seventy-nine percent of the expenditure was spent on staff costs and direct project costs.

The Deficit

The deficit of £43,274 (2018/19) was funded by from the reserves from 2017/18 (£56,754), bringing the reserves figure carried forward to 2019/20 £13,480. The £13,480 was made up of £10,091 restricted funds and £3,389 unrestricted funds.

NSUN again navigated a difficult year, building the budget through securing core funds from Tudor Trust (£30,000) and Lankelly Chase (£30,000) and a Capacity Building and Peer Support partnership project agreed with Mind (£30,000).

Significant savings were made as a result of the office closure (January 2018), reduction of staff hours and staff redundancy. An Associate

Model was formally introduced, which allows expertise and capacity to be drawn in to the team as and when funds are available to undertake work.

Fundraising

Fundraising activity continues to be a priority especially in securing longer term funding beyond 12 months.

Applications to Esmee Fairbairn,
Tudor Trust and the National Lottery
Community Fund will be progressed and the membership charging policy will be introduced in 2020.

What our members have to say...

"The connection made us feel like we weren't alone, it enabled us to attend events, make links and learn from good practise." "Join forces with other organisations that are working against cuts to public funding."

"The NSUN newsletter leads from the front in making information accessible."

"Move away from Londoncentricity."

"I use your newsletter regularly to compile our own in house staff briefing."

"The bulletin is a real lifeline it means I can find out about what's going on across country."

"NSUN doesn't shy away from conflict and is not a passive organisation."

"Ensure leadership training is offered in different areas throughout the country."

"Our voices need to be heard in arenas outside of the mental health world too." "We need to build effective peersupport networks, which would pay people."



We are here to make sure the voice of experience is heard.

The NSUN Board of Trustees submits its statutory Report and Accounts for the year ended 31 March 2018. The Trustee's Report and Financial Statements have been prepared in accordance with the Companies Act 2006, the Charities Act 2016 and comply with UK Generally Accepted Accounting Practice (GAAP). They also comply with the Accounting and Reporting by Charities: Statement of Recommended Practice (SORP) in accordance with the Financial Reporting Standard, also known as the Charities (FRS 102) SORP. Exemptions from disclosure: This annual report does not omit or withhold any reference or administrative details.

Public benefit statement

In reviewing our aims, objectives and activities, the trustees have taken into account the Charity Commission's general guidance on public benefit. The trustees ensure that the activities undertaken are always in line with the charitable aims and objectives as set out in NSUN's governing document. This annual report does not include no exemptions from disclosure.

National Survivor User Network

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NSUN would like to thank our supporters who 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

- Awards for All
- Esmee Fairbairn
- Health and Wellbeing Alliance
- Lankelly Chase Foundation
- Mind
- NHS England
- Trust for London
- Tudor Trust

And of course all of the individuals who have generously donated through our #NSUNThrive10 campaign.

Together we are stronger