

# NEWSLETTER

March 2009, Issue No. 5

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## Introducing Sarah Yiannoullou

I joined NSUN as the manager 2nd March 2009 . Previously I worked across the south east as a Service User Involvement Manager for 3 years in a role that had aims not dissimilar to those of NSUN. My background was originally in the arts but life experiences (as often happens) took me on a different journey, one that has led me here.

I have been involved with service improvement and involvement for over ten years and have worked in both the statutory and voluntary sector. My concern has always been to influence the quality of services for the better so that the experience of people using them is improved.

The aims of NSUN build on the work of so many people over so many years, who through their own personal experiences have been motivated and driven to challenge systems and practices and campaign for positive change.

At a time of complex service reform and transformation I feel privileged to have the opportunity to assist in getting our voices heard not just at the grassroots of service delivery but also at government level.

Whether our chosen routes are through consumerism, political activism or self help we all have common aims and goals. Coming together for collective activity, to share what helps and what hinders and to offer mutual support on a national scale is an exciting prospect which is definitely being realised, against all the odds!

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## Peer Support

NSUN is looking to set up a peer support network for service user involvement workers.

The planned group will be made up of workers from around the country and will meet on a regular basis to support each other share good practise and action learning.

There will be opportunity for members of the group to share their own experience within their roles and to also provide training and insight to the rest of the group.

If you currently work in a user involvement role at a local, regional or national level and feel you would like to be involved please contact:

Amma Djan on 0845 602 0779 or email [amma.djan@nsun.org.uk](mailto:amma.djan@nsun.org.uk) to register your interest.

## Mellow: Its all about Relationships

**DATE: TUESDAY 21st April 2009**

**TIME: 10.00AM - 3.30PM**

**STOKE NEWINGTON WEST RESERVOIR CENTRE, GREEN LANES, LONDON N4 2HA**

A free day event that will launch the evaluation report of the 4Sight programme that promotes the mental well being of African and Caribbean men.

You will hear from 4Sight members how the programme has improved their mental well being and supported their recovery.

The event will showcase the work of the 4Sight programme and its approach.

Motivational speakers, Inspirational Poetry and Lunch provided.

## Why Not Join Us

To register or for more information contact:-  
**Tigist Teferi on 0207 655 4170 or email**  
[mellow.centre@eastlondon.nhs.uk](mailto:mellow.centre@eastlondon.nhs.uk)

## Meet the Management Committee:

### Alisdair Cameron



MH user and carer body.

He is a director of NAGAS (Newcastle and Gateshead Arts Studio), vice-chair of MHNE, and a board member of UKAN (United Kingdom Advocacy Network) and of NSUN (National Survivor and User Network).

Alisdair Cameron has variously been an academic historian, a lawyer and a user of mental health services, in between stretches of generalised community activism.

His day job is as team leader at Launchpad, the mental health service user involvement project for Newcastle upon Tyne, and he is also co-chair (with Mish Loraine) of the Northumberland, Tyne and Wear Service User & Carer network, and has been a leading light in the establishment of a North East region-wide

In spare moments he shuffles all of the letters from the aforementioned acronyms and sees what they can spell out

## User involvement excludes BME communities

Black and minority ethnic service users have had it with tokenistic 'service user involvement' initiatives that are simply about getting enough black faces at committee meetings for NHS mental health trusts to be able to tick a box and claim that they have been 'involved' in service design and delivery.

So says a new, hard-hitting report on BME mental health service user involvement published this month (March) by the National Survivor User Network (NSUN) of user-led groups and organisations, and Catch-a-Fiya, a BME mental health service user forum.

Dancing to Our Own Tunes reports findings from a national consultation with BME and white British service users and survivors about their experience of 'involvement', both within the statutory sector mental health services and within the service user/survivor movement.

The report identifies numerous barriers to involvement, at individual and community level.

BME service users' experiences of mental health care are frequently so bruising that they want never to have any contact with services again. Having emerged from hospital, in many cases people's priorities are getting their lives back on track, not sitting on trust committees and going to meetings. There is also the stigma within BME communities, and society in general, of being known to have used mental health services. used mental health services.

But the report highlights the overt and covert racism BME service users encountered when they did get 'involved' with NHS trusts. BME service users talked about having to 'dance to their tunes', and not being able to talk about what mattered to them and their communities.

They wanted to be part of trusts' decision-making processes, not just a token black rubber stamp: 'That's the crux of the matter, are we designing a service together or are we panel beating an already existing system?'

They also described both covert and overt racism within service user involvement groups where they felt silenced when they wanted to talk about their experiences of race discrimination within the mental health system. One person said: 'People have said to me, just openly, you're here as a service user, you're not here as a black person, so don't go on about race. But look at my skin. I cannot take off my skin.'

The report calls for a radical redefinition of service user involvement to be up-ended. It should be about supporting individual BME service users and groups at grassroots level to build their confidence and capacity to set the agenda themselves, and tell services what needs to change.

'Increasing involvement is often seen as increasing the number of black bodies on committees, but people's experience of being involved in this way was overwhelmingly negative,' says the report's author, service user and independent researcher Jayasree Kalathil. 'We have to shift the locus of leadership to the communities whose involvement we are seeking, build the capacity of these smaller groups, and create a strong political voice not just on mental health but also on racism.'

NSUN will be working with Catch-a-Fiya and other black service user-led organisations at local and national level, to take forward the recommendations from the report.

Dancing to Our Own Tunes can be downloaded free from [www.nsun.org.uk](http://www.nsun.org.uk)

## Cont. Recommendations

- 1 **Set up a national steering group to take the work forward**
- 2 **Shift the locus of leadership to service users from BME communities.**
- 3 **Support the diversity of work already being undertaken by service users within their own communities, and create alliances with other social development initiatives.**
- 4 **Build capacity of smaller groups, through decentralising resources, mentoring and peer support.**
- 5 **Establish an organised political voice to comment and campaign on racism and mental health and facilitate networking and information sharing between national and local groups and organisations.**

## Job opportunity

### NSUN Operational Accountant

The National Survivor User Network (NSUN) is dedicated to creating a network that will engage and support the wide diversity of mental health service users and survivors across England in order to strengthen the user voice. It supports individuals, existing groups and networks through practical support. It also facilitates and enables the widest range of survivors and service users to have a voice in informing and influencing local, regional and national developments in mental health.

We are looking to recruit an experienced Operational Accountant to provide an overview of NSUN's financial systems and structures; to ensure they are managed efficiently and transparently; and to provide direct support and training to the Administration and Finance Officer.

**Hours: 2 days a month**

**Salary: £300 for two days per month**

We are looking for someone who is part qualified or training towards a recognised accountancy qualification E.g. ACCA / CIMA and who also has at least 2 years experience in an accounting environment. If you are interested in the role:

Please email or phone Sarah Yiannoullou for Application Pack  
Sarah.yiannoullou@nsun.org.uk  
0845 602 0779 **Closing date: 24th April 2009 at 12pm**

## Funding opportunity

### The Northern Rock Foundation grant programmes:

Independence and Choice Giving people with mental health problems, people with learning disabilities, older people and carers a choice of excellent services that help them to become or remain independent.

Building Positive Lives Helping people who lack self-confidence or motivation, or who face discrimination, to have the individual support they need to lead more positive and fulfilling lives. Safety and Justice Reducing the incidence and impact of domestic abuse, sexual violence, prostitution, child abuse and hate crimes, by investing in better support for victims. Culture and Heritage Inspiring, enjoyable and diverse culture programmes and events that raise our region's profile and make it a better place for everyone to live and enjoy life.

They offer core support, project grants and grants towards capital costs within revenue projects (e.g. small items of equipment). They do not offer grants for building projects. They are happy to make grants to support salaries and employment costs, and if your proposal includes these, you should read their additional guidance on employing people on website below before applying.

They will support tried-and-tested activities that can prove they are still meeting a clear need, and genuine innovation where it is warranted. It is up to you to say how your chosen approach fits within the aims of their programmes.

They encourage and support organisations to work together where this will produce better results for their beneficiaries. They will accept consortium applications, although our grant must be made to a specified lead organisation.

They make most of our grants over one, two or three years, but they will consider making grants over longer periods if there is a good reason to do so.

The Foundation has different grant application processes: one for requests from £1,000 to £20,000; the other for requests over £20,000. Make sure you complete the correct application form. See website below for further details.

The Northern Rock Foundation The Old Chapel, Woodbine Road, Gosforth, Newcastle upon Tyne NE3 1DD Tel: 0191 284 8412 Fax: 0191 284 8413 Minicom: 0191 284 5411 Email: [generaloffice@nr-foundation.org.uk](mailto:generaloffice@nr-foundation.org.uk) Website: [http://www.nr-foundation.org.uk/tn\\_applying.html](http://www.nr-foundation.org.uk/tn_applying.html)

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## Open Up: WNUSP

Africa is a beautiful place. Uganda was called 'the pearl of Africa' by Winston Churchill. The people are friendly and are pleased to see us. The pace of life is gentler, not so buzzing busy and local people take time to talk to you.

Our conference began at 9am sharp. Our master of ceremonies was Julius Lutaakome Kayiira, Director, Mental Health Uganda.

The Opening was by Mrs Patricia Athieno, President of Mental Health Uganda, welcoming our conference to Uganda. We also were greeted by Hon Alex Ndeezi MP representing people with disabilities in the Central region of Uganda.

Delegates from the various regions were welcomed: Latin American, Asian, European and African delegates. There was an artistic greeting by the KiKa Dance troop from Kampala on the convention stage. The dancing was very good, really energetic and full of the joys of life.

The board of WNUSP includes directors Moosa Salie [South Africa], Tina Minkowitz [USA], Gabor Gambos {Hungary}, Iris Hoelling [Germany].

Tina Minkowitz gave a very good presentation describing the United Nations Convention, [Convention for the rights of People with Disabilities] which was signed in 2007.

The convention is a very important step for user survivors. It restores the imbalance that user survivors suffer through having a diagnosis. Some forms of psychiatric treatment could be interpreted as torture or violation and are consequently outlawed.

That includes ECT and coerced medication. Over 40 countries have ratified the convention including the UK. We have yet to ratify and implement it.

Later there were two workshops on Health Alliances by Gabor Gambos and one on torture by Tina Minkovitz. Gabor wanted to encourage advocacy to help or be helped by another you trust, but someone who does not lead or dominate.

The principle is also included in the CRPD. The mood of the conference is sceptical of psychiatry especially ECT, over use of pharmaceutical drugs, forced or coerced treatment. User Involvement now becomes a right not just good practice and any sensible barrier in society is now open for challenging by the mental health community.

UK delegate Peter Munn, speaking for Mary Nettle who could not attend, reported that in the UK there is lack of unity among major players. It's a shame the UK is not united in user advocacy - perhaps the conference can address this issue later on?

The conference can be overpowering; very stimulating to the senses. In the evening I got a graphic account by Moosa Salie and Annie Robb of the anti-apartheid movement in Cape Town during the last days of the inequitable regime. **Joe Kelly**

## Poet's corner: Leadership with meaning

I collate my thoughts into replenishment  
Self directed recovery enabled reinvented  
Taught by self realisations  
Caught by the web of stratifications  
I am enticed into a spectrum of forums  
Debating issues of dignity and decorum  
Am I a Salmon lead up stream  
Or the nature that leads the Salmon up the stream  
All I know is the Salmon is included  
And my nature is an energy of social inclusion  
A chi or a metaphor as I open the door  
To elaborate on this journey or fate some more  
I now translate and in change instigate  
In order to lead we have to follow  
The inspiration leads us by way of tomorrow  
That day we borrow from time not sorrow  
As collapses an enigmatic fight of sides  
A tribal gathering of fluttering lights of pride  
Harmonious patriarchs standing breathing equity  
Abandoning the stance of inequality  
Understand this moment the leadership of life.  
The journey that unearths the good fight.

R A Cowley

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