

# Dancing to our own tunes

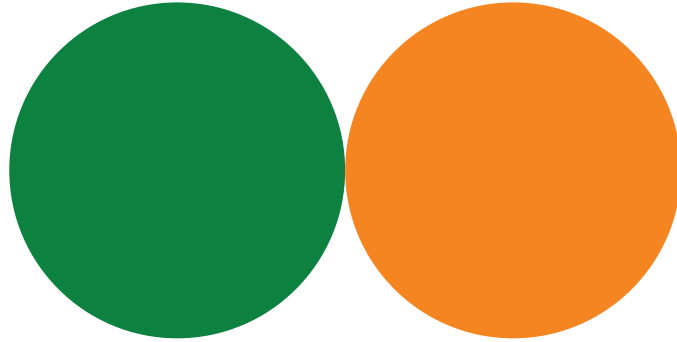
Reassessing black and minority ethnic mental health service user involvement

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## **Dancing to our own tunes**

Reassessing black and minority ethnic  
mental health service user involvement

Jayasree Kalathil



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# Foreword

As a generic service user/survivor mental health network, the National Survivor User Network (NSUN) made a commitment to ensure that the voices of those from marginalised communities were an integral part of the development of a national network.

Following the launch event on 24th March 2009 of the original report, *Dancing to our own tunes*, it was crucial that momentum and enthusiasm was not lost. NSUN and Catch-a-Fiya continued to work in partnership to take the work forward over a time limited period. Service users provided the direction for this work, with service users from black and minority ethnic communities taking on the leadership.

I want to personally thank the members of the TOOTS group (the group set up to take the recommendations forward) who shared their expertise and experience so openly and generously. It is important that we review this work regularly and communicate what has worked, what hasn't worked and why. It is also our responsibility to build strong partnerships and ensure that the learning and vision of important programmes such as Delivering Race Equality in Mental Health is not forgotten or lost.

Most importantly, we want to see and experience meaningful involvement and leadership within the BME service user community. Mainstream services still need to change significantly so the needs of an increasingly diverse population can be better met. For NSUN and The Afiya Trust, who hosts Catch-a-Fiya, this work is a continual process of addressing the problems and possibilities.

**Sarah Yiannoullou**

*Managing Director – National Survivor User Network*

The release of *Dancing to our own tunes* marked a pivotal moment in the collaboration between the National Survivor User Network and Catch-a-Fiya. The Afiya Trust is putting on record its continuing commitment to develop and nurture service user leadership and involvement, both within the organisation and outside through the strategic and policy forums we work with.

This report launches the TOOTS charter and guidelines for involvement. It comes at a crucial time when both user involvement and the race equality agenda are underplayed and sidelined in mental health policy. It is our responsibility to ensure that the service user movement as a whole and black and minority ethnic user movement in particular are supported to continue doing the great, and sometimes difficult, work they do in challenging and changing the mental health system.

The Afiya Trust, with Catch-a-Fiya, will ensure that we do this by finding resources where possible, using our influence in strategic bodies, and continuing to develop influential relationships with other black and minority ethnic and generic organisations. With NSUN, we will work to take the recommendations from the report forward and to develop and incorporate the charter and guidelines into national standards for service user leadership and involvement.

We join NSUN in thanking members of the TOOTS group for their excellent work in producing the charter and guidelines.

**Patrick Vernon**

*Former CEO – The Afiya Trust*

**Odi Oquosa**

*Former Independent Chair – Catch-a-Fiya*

# Introduction

In 2008, the National Survivor User Network (NSUN)<sup>1</sup>, in partnership with Catch-a-Fiya, the national black and minority ethnic mental health service user network hosted by The Afiya Trust<sup>2</sup>, undertook a consultation to explore the barriers to and solutions for meaningful participation of service users and survivors from black and minority ethnic (BME) backgrounds in mental health user involvement initiatives. Looking at the involvement in both service and policy driven initiatives and in generic user-led groups, this consultation aimed to develop recommendations for good practice in increasing involvement of and partnership working with service users and survivors from black and minority ethnic backgrounds and to outline a programme of work to be undertaken by NSUN to stimulate positive change in this area. The report of this work, *Dancing to our own tunes*, marked a pivotal moment in NSUN's development by starting a systemic process for partnership working and embedding this in its overall aims and objectives as a network to empower and support mental health service users. In the following years, NSUN continued to work in partnership with Catch-a-Fiya and The Afiya Trust to take forward the recommendations from the report. The partnership also sought to use the report and its recommendations to influence user involvement in mental health in general, by feeding into national policy development and practice. The report has reached far and wide, and its recommendations have been used by a range of organisations, including NHS trusts, voluntary sector organisations and user-led groups, to influence national, regional and local policy development.

## Aims of this review

This review has the following specific aims:

1. To take stock of the work done to implement the recommendations from the initial report, reflecting on internal organisational initiatives.
2. To present a quick overview of the current status of black and minority ethnic user involvement in mental health, reflecting on external policy and political contexts.
3. To present the 2008 report in the current contexts and reflect on future priorities for development.

## How the review was done

The review is based on:

- Analysis of documents of work undertaken by NSUN and The Afiya Trust, including strategic plans and evaluation reports.
- Reflections of service users/survivors who were part of the initial consultation and of the steering group members set up to take the recommendations of the report forward ('the TOOTS group').
- Reflections of external stakeholders involved in promoting race equality and user involvement in mental health.
- Desk research to estimate the reach and influence of the 2008 report.
- Analysis of recent policy documents in health and social care, including the new mental health strategy, No health without mental health, and the legacy documents from the Delivering Race Equality (DRE) programme. The review forms the first part of this report. The second part reproduces the 2008 report in full, as the findings and recommendations are as relevant today as they were three years ago.

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1. The National Survivor User Network (NSUN) is an independent network of individuals and groups who have direct experience of mental distress and/or using mental health services. [www.nsun.org.uk](http://www.nsun.org.uk) [Accessed 11/10/11]

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2. The Afiya Trust is a national charity that works to reduce inequalities in health and social care provision for people from racialised communities. [www.afiya-trust.org](http://www.afiya-trust.org) [Accessed 11/10/11]

# A note on the terminology used

## **Service users and survivors**

People who have experienced mental distress or have used/received mental health services use several words to refer to themselves. The phrase 'service users/survivors' is used in this document to reflect the two terms that are most often used currently.

## **BME**

There is often a debate around the terminology used to refer to communities minoritised in relation to the local population on the basis of their 'racial' or 'ethnic' origin. No single term is fully capable of capturing the vast diversity,

difference and similarity within these communities. Currently, 'black and minority ethnic' is the term consistently used in census, survey and routine administrative data. This term refers to a range of communities including established groups (e.g. African, Asian, African-Caribbean), 'new' migrant communities (e.g. people from Eastern European countries), refugee and asylum seeker communities, transient communities (e.g. the traveller community), and groups often referred to as 'invisible minorities' (e.g. the Irish community). Hence we have chosen to use this term for the purposes of this review and report.



# **PART 1**

## **The Review**



# Reception & influence of the 2008 report

*Dancing to our own tunes* was launched in March 2009. Since then, the report's author and representatives from NSUN and Catch-a-Fiya have presented the findings and recommendations at various meetings, seminars and conferences, including the British Sociological Association/Survivor Researcher Network seminar series in 2009. Articles based on the report were published in *Community Care*, *DiverseMinds*, *Mental Health Today*, *Agenda*, and on online news forums like [blackmentalhealth.co.uk](http://blackmentalhealth.co.uk). The report has been widely disseminated through voluntary sector websites and research databases (for example, *Mental Health in Higher Education*, *SCIE-Social Care Online*, *NHS Evidence*).

As part of this review, we conducted desk research to get an idea of the reach of the report and asked external stakeholders whether and how they had used the recommendations in their work. This showed that the report and its recommendations have been quoted as evidence in developing more inclusive policies for user involvement in England and outside. For example, the North Essex Partnership NHS Foundation Trust's service user and carer involvement strategy (2010) quotes the recommendations from the report as specific strategies to increase effective user involvement from black and minority ethnic communities. A report, making a case for developing peer support, submitted to the Mental Health Commission of Canada (O'Hagan et. al. 2010) quotes from our report to highlight "the need to move beyond a singular focus on the shared experience of madness and develop cultural competency understandings and practices" (p31-32).

The report and its recommendations have fed into user/carers involvement policy development and training within voluntary sector organisations like *Mind* and *Rethink*.<sup>3</sup> *Awetu*, an organisation working to foster the mental wellbeing of black and minority ethnic communities in Wales, is using the report as evidence to support a funding bid

to appoint user empowerment and advocacy coordinators to work with the service users they support.

*"[The report] assists tremendously in helping to give a voice, not only to the people/families who are familiar with services, but also to those people or organisations who are not able to voice those concerns more articulately and with authority, but also has the credible evidence to back up their concerns and arguments. Without this report, I would not have the full picture of the why's and wherefore's or the backing of such robust and recent evidence. If Awetu are successful in its bid, then you can be sure that I will be using every inch of the document to fulfil and sustain the posts and the groups that we hope to establish around Wales."*

Director, *Awetu*

The Delivering Race Equality programme's review report acknowledges that "the case for understanding the complexity and the need for greater inclusivity within the service user movement was set out eloquently" by the service users whose views are expressed in our report (Wilson 2010, p34). Responding to our external stakeholder consultation, the former director of the DRE programme said:

*"I think it is a seminal document, which coherently and eloquently sets out the case for wider and more meaningful black and minority ethnic user involvement. It is a clear voice for why the status quo is not acceptable. I also think it raises some important issues in relation to how the BME and broader white service user involvement movements interact, and identifies issues which also need to be addressed by each – together – to support moving forward more cohesively. In addition, it says to black service users that although there is a history of 'stepping up to the plate' more can and should be done to contribute to change...I believe it is important that this work is acknowledged, accepted and used as a key part of the evidence base to inform the service user movement and make it more effective; but also importantly, to influence the way in which mental health services are commissioned and delivered. At a time when*

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3. Alison Faulkner, email response to this review. See also, Faulkner (2009) "User involvement: a brief literature review" for the *Mind* Involvement Strategy. [http://www.nsun.org.uk/getinvolved/survivor\\_involvement](http://www.nsun.org.uk/getinvolved/survivor_involvement) [Accessed 23/10/11]

*the role of service users and patient and public involvement in general is uncertain in terms of the wider debate about the direction of public sector policy, it is good that the Dancing to our own tunes report exists as a line in the sand.”*

Melba Wilson

Clearly, the report has reached a wide audience and has helped inform black and minority ethnic mental health service user/survivor involvement. However, it is difficult to say whether this has had any lasting and tangible impact on the way user involvement activities are set up and run. The review comes at a time when there seems to be a widespread view that user involvement as an agenda is losing prominence and the clear policy direction it had is getting diluted. In the next section, we take stock of the current status of user involvement in mental health policy and priorities.

## **Enabling effective user involvement: Recommendations from *Dancing to our own tunes***

- Link work to change mental health services with broader race and rights based initiatives in education, forensic services, citizenship rights, social inclusion, employment, income generation etc.
- Build relationships between mainstream groups and black and minority ethnic groups, between communities and between professionals and service users/survivors.
- Enable professionals from black and minority ethnic communities to think about race related issues in their practice.
- Actively seek out groups and organisations working locally, highlight their work and endeavour to support and sustain them.
- Support local organisations to develop autonomy and access sustainable resources.
- Invest in people’s potential. Acknowledge that mental health is only one aspect of a person’s life.
- Mobilise solidarity and support through peer groups, sharing learning and enabling networking between groups.
- Offer mentoring and support to people who might be newly interested in user involvement. Help them identify their interest areas and ask questions to clarify the scope of involvement and their role in it so that they can make informed choices about participating.
- Develop national, regional or local standards for involvement. Mobilise a united front to uphold these standards.
- Evaluate user involvement initiatives, focusing on outcomes rather than content and processes.
- Document work in user involvement so that we can learn from our experiences, celebrate achievements and create our own history.

# User involvement: where are we now?

At the time the 2008 report was being written, it was clear that engaging people who use services in developing those services, or 'user involvement', had become an intrinsic part of mental health policy. However, with the coalition government taking charge, there have been some significant changes affecting mental health policy and service delivery, which makes it difficult to be quite so categorical in making such an observation. This chapter examines this changing policy context and presents the reflections of service users/survivors we contacted for this review.

## The policy context

The National Mental Health Development Unit (NMH DU), an organisation which focused on developing national work programmes, policy and guidance, has shut down. The Delivering Race Equality programme, which helped keep race equality on the agenda and supported work around the country, has ended. A new Health and Social Care Bill, bringing in large scale changes to the way NHS functions, is making its passage through Parliament. We now have a new mental health strategy with renewed priorities and objectives, but no clear implementation strategy as yet. There is now more talk of service user and carer 'choice and control' in the personalisation and recovery agendas, but the evidence on how well this works out in practice is mixed.

All these changes are happening alongside large-scale cuts to public spending and an overhaul of the welfare and benefits system which is causing a great deal of misery and anxiety for disabled people and mental health service users. The impact of all of this on user/survivor self-determination and involvement is, to say the least, uncertain. The 2011 mental health strategy NMH DU's predecessor, the National Institute of Mental Health in England (NIMHE) developed a programme and guidelines for user involvement called 'Making a real difference' (MARD)<sup>4</sup>, based on the recommendations from a report on

strengthening user and carer involvement in NIMHE (HASCAS 2005). MARD guidelines and tools for developing and evaluating involvement were expected to enable a systematic approach to user involvement and to fulfil the principles set out in the 2006 white paper, *Our health, our care, our say* (DH 2006a). With the closure of NMH DU and the changes in policy, it is not clear how these guidelines and tools will be used in the future.

The new mental health strategy, *No health without mental health* (DH 2011a), contains statements of the coalition government's commitment to "putting more power into people's hands at local level." The strategy also states that "users of services will increasingly be able to take decisions about their own healthcare. They and their carers may wish to become involved in the planning and design of local services" (p26).

The new mechanism for the public, including service users and their families and carers, to involve in influencing mental health services, it would seem, is the Local HealthWatch, introduced in the NHS white paper, *Liberating the NHS* (DH 2011b). Local HealthWatch is expected to feed into the new 'consumer champion', HealthWatch England, based within the Care Quality Commission, and through it to the National Commissioning Board. The role of HealthWatch England in the context of mental health, according to the mental health strategy, is "to ensure that the voices of people with mental health problems, including children, young people and their families – who can often be marginalised – are central to the assessment of quality in specialist mental health services and in health services more generally" (DH 2011a, p45).

At face value, these objectives seem to reflect one of the recommendations for effective user involvement from *Dancing to our own tunes*: "Support agendas set by communities at the local level." For this to happen, the report says, we need to ensure that local groups have the capacity, resources and the autonomy to sustain their work without being controlled by larger, influential organisations. But the mental health strategy document does not contain a clear implementation plan to show how marginalised groups of people who will

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4. The research that led to the development of MARD and the guidelines and tools developed by the programme are available at [http://www.nsun.org.uk/getinvolved/survivor\\_involvement](http://www.nsun.org.uk/getinvolved/survivor_involvement) [Accessed 23/10/2011]

already be on the lower rungs of local social hierarchies will be supported to participate in Local HealthWatch and make decisions for themselves. The “call to action” on the mental health strategy did not include any user-led organisations or organisations working with black and minority ethnic communities, as stated by both The Afya Trust and NSUN in a press release dated 11th February 2011:

*“What concerns us is what isn’t in the strategy – no acknowledgement of BME mental health service users or the service user-led agenda. In the strategy’s call to action document, no service user-led or BME-led organisations are listed, yet we have been working with the National Mental Health Development Unit and the Department of Health.”*

### **Race equality in mental health**

The Delivering Race Equality Action Plan (DH 2005) acknowledged the existence of institutional racism within NHS discussed in the report of the inquiry into David Bennett’s death (Norfolk, Suffolk and Cambridgeshire SHA 2003). The programme had several successes, including the work done by community development workers across the country, training of frontline staff in race equality and cultural capability and involving communities in assessing and suggesting solutions to their mental health needs through the community engagement programme.

However, its closure while failing to address institutional racism and the continuing racial inequalities within mental health services have made several services users, communities and campaigners feel that race equality is taking a back seat in mental health policy. The review report of the five years’ work taking this action plan forward seems to distance the programme from the earlier call to address institutional racism:

“The David Bennett response was linked with DRE by DH but was not the only motivation for DRE. The later disagreement about whether institutional racism exists and what form it takes was therefore de-stabilising for DRE, as the foundations were already based on a particular paradigm that was generally accepted by the public and professionals. Therefore, the linkage, although important, proved to not be helpful to the wider ambitions of DRE and alienated those who did not believe in institutional racism” (Wilson 2010, p43).

The perceived ‘disappearance’ of the race equality agenda from mental health policy is also linked to the continuing problems faced by black and minority ethnic communities within mental health services. The 2010 Countme in census shows:

- Admission rates remain higher than average among some minority ethnic groups, especially Black and White/Black Mixed groups for whom rates were two or more times higher than average in 2010 (six times higher than average for the Other Black group).
- Detention rates were higher than average among the Black, White/Black Caribbean Mixed and Other White groups.
- Although there have been annual fluctuations in seclusion rates, they have been higher than average for the Black, White/Black Mixed and Other White groups, in at least three of the six censuses.
- The rates for being placed on a CTO were higher among the South Asian and Black groups by 22 to 106 per cent.

The new mental health strategy has six shared objectives, including “more people with mental health problems will recover” and “more people will have a positive experience of care and support.” It has been pointed out that, unless specific issues affecting groups of people are not addressed strategically, it would be entirely possible to achieve these objectives overall, while leaving behind sections of society already experiencing disproportionate, inappropriate and discriminatory treatment within mental health services. Crepaz-Keay (2011), for example, argues that whether you achieve the six objectives in the strategy will depend on:

*“...where you live, what you earn, how old you are, what your diagnosis is, whether you have any other disabilities, what colour your skin is. This matters because it is entirely possible to achieve all six objectives without making a jot of difference to a single young black man with schizophrenia. Will this be different in five years time?”*



## The DRE Ambassadors Programme

Perhaps the only consolidated national programme for user/carer involvement aimed at people from black and minority ethnic communities so far was offered by the DRE Ambassadors programme. The programme ran from 2007–2010 (in the early months as the champions programme).

The programme aimed to link communities into the overall DRE programme and strategic developments so that they could influence and improve the outcomes and experiences of mental health services for black and minority ethnic communities. The structure to do this was a national network of independent service users/survivors and carers who would represent the voices and views of their local/regional communities.

The programme's structure – local and regional voices and views influencing national policy and practice – is one that is supported by the recommendations in *Dancing to our own tunes*. It was successful in bringing together dedicated and creative people. However, whether the ambassadors had any influence over the DRE programme and its agenda as a whole is doubtful. An evaluation of the programme undertaken by the Social Perspectives Network (Bogg 2011) showed that “wider application and roll-out of the work was limited and there were structures and systems that acted as a barrier to the successful and effective implementation of the programme” (p38). The evaluation highlighted these key problems:

- insufficient and changing structures and processes affecting stability and consolidation of involvement
- lack of role in decision making affecting the ambassadors' influence over the race equality agenda and its national, regional and local delivery
- inconsistent application of the ambassador model and support for it across the country
- questions about the representativeness of ambassadors
- lack of clarity of purpose and about demonstrating outcomes: ambassadors as

‘add-on’ to the existing programme

A key question to ask is why a government-led national involvement programme was set up by hand-picking individuals while local, regional and national user-led groups and networks of black and minority ethnic service users and carers already existed. National programmes for black and minority ethnic service user involvement would have had more credibility, influence and, arguably, a lasting legacy if they:

- actively sought out groups and organisations working locally, and endeavoured to support and sustain them
- supported local organisations to develop autonomy and access sustainable resources
- invested in people's potential
- mobilised solidarity and support through peer groups, sharing learning and enabling networking
- developed national, regional and local standards for involvement

*(Dancing to our own tunes 2008)*

## Reflections of service users/ survivors

As part of this review, we asked members of NSUN and Catch-a-Fiya who took part in the consultations for the 2008 study and formed the TOOTS group (the group set up to take the recommendations forward – see next chapter) to reflect on the current status of user involvement, based on three broad questions:

- 1) Would you say that user involvement is as strong a policy and practice now as it was three years ago, especially in the new mental health strategy and in rapidly developing agendas like personalisation and recovery? What is the status of user-led or user-controlled groups in today's context?
- 2) Would you say that there have been changes in the involvement and participation of users and survivors from black and minority ethnic backgrounds in the last few years? What do you think of the current status of race equality issues in mental health?
- 3) What are your thoughts on the recommendations made in the initial report from today's perspective? Do you have any comments to add to these?

The responses were collected by email correspondence or by telephone. We were not successful in contacting everyone. Of the people who responded, five had moved away from mental health related work; three of these had chosen not to involve themselves entirely while the other two still kept abreast of information and developments. The decision to move away from mental health work was personal in one case, but in others it arose from a sense of accumulated dissatisfaction with the way their involvement was valued or with what they thought they could achieve. This reflects comments in the earlier report about the real possibility of user involvement achieving lasting changes.

It has to be kept in mind that the following sections are not presented as categorical evidence of issues in user involvement in the current context, as the review did not follow a rigorous methodology but an informal consultation. These are reflections and feelings expressed by people (11 in total) who work as user/survivor experts, campaigners, researchers and trainers, voluntary and statutory sector workers, educators and activists locally and nationally. Nevertheless,

these are valuable insights and, wherever possible, they are linked with documented evidence.

### Stronger presence, uncertain influence

Overall, the feeling was that user involvement as a concept and the idea that service users/survivors are 'experts by experience' had better visibility over the years. But the application of the concept and how it was supported had been patchy.

*"On the one hand, there have been more legal stipulations and guidelines about user involvement and I'm aware that there are more opportunities than there were in the past to give views to the government, influence organisations, act as a trustee, take part in key areas such as service reviews and inspections, research, staff recruitment, staff training etc. On the other hand, it has been discouraging that so often the involvement offered has been on a token basis."*

Involvement structures such as HealthWatch are shifting the focus away from mental health and towards generic engagement of 'patients'. The 'parity of esteem' between mental health and physical health, celebrated in the new mental health strategy call to action, while theoretically moving mental health away from its stigmatised position, may have a detrimental effect on what say mental health service users have in how the NHS is run and how services are commissioned.

*"...I'm sensing a different current now – pushing towards generic involvement rather than mental health specific, with the argument put forward that this is progressive – and why should mental health service users 'ghettoise' themselves? But it may be more about cost saving and keeping the agenda more controlled and less threatening."*

The feeling was that the main call to 'generalise' involvement is from statutory bodies and mainstream non user-led voluntary sector rather than from service users themselves. The idea that this has to do more with funding rather than a belief in a holistic human nature, and hence dealing with distress, came up several times.

*"...the reality is that when economic matters are paramount, money for involvement is squeezed like everything else. So in [my local area] the main mental health service user group that was involved across all the*

*planning processes has been axed, and something much more slimmed down, cheaper and general has taken its place."*

## **Risks to rights-based approaches**

Looking at these shifts in the context of the recommendations made in the 2008 report, it seemed that the call to contextualise user involvement in "a broader social change agenda" and the rights-based approach that this would require is what is under threat. Two main concerns came up in this context:

- 1) The overall increase in compulsion in mental health services, as evidenced by the increase in compulsory admissions by 18 per cent in the last two years (NHS Information Centre 2011) and the increased use of supervised community treatment orders (Lawton-Smith 2010).
- 2) The risk to the wellbeing and lives of mental health service users and other disabled people due to the changes to the welfare and benefits system that the government is bringing in.

People's ability and interest in taking part in user involvement activities is diminished when their ability to meet their basic needs is itself threatened. This was identified as one of the barriers to user involvement in the 2008 report which, it was felt, had become worse in the current scenario:

*"...the big fight at the moment is with the disability movement, and the benefit changes that the government wants to bring in."*

*"It could and would be progressive if service users of all groups and ethnicities were choosing to come together and fight for rights and better services – perhaps in the fight back against the current government's policies on welfare reform that is happening."*

No health without mental health states that 'fairness – equality, justice and human rights' is one of the guiding principles and values of the mental health strategy. But the cuts to services, the reform agenda that is affecting people negatively and the disappearance of funding to user/peer groups contradict this principle.

*"The 'rights based' approach...is certainly under attack on various grounds – that we can't afford it, that it leads to unrealistic expectations and 'wrong' attitude...I think this shift will impact on involvement generally and in particular on the involvement of BME communities."*

## **New challenges to BME user involvement**

Black and minority ethnic service user-led groups are continuing to gain momentum and strength, and "*dancing to their own tunes.*" The 2008 report showcased SIMBA in South London, one of the early groups to exemplify self-determination in involvement, and many more were mentioned in the reflections, including Kindred Minds in London, The TwoWay Street in Bristol and the Maat Probe group in Sheffield, to name just a few. There was a general feeling that the importance of partnership working between service users/survivors of all backgrounds and the need to involve people from black and minority ethnic groups had been made forcefully by user groups and service users. However, the application of this in practice, it was felt, was patchy.

*"My overall impression of involvement and participation of users and survivors from BME communities is that the struggle for this is still an uphill one. I have been dismayed by the government's continuing failure to grasp the particular issues faced by people from BME communities who use services, e.g. the inadequate professional grasp of varying cultures, the fact that people from some BME communities are still overrepresented in the more coercive parts of the Mental Health Act, the tendency for people from BME communities to receive more limited services etc."*

Several national programmes, funded by the Department of Health and others, and working on recovery, challenging stigma and discrimination, delivering personalisation etc. were criticised for their lack of progress in working meaningfully with black and minority ethnic service users and their organisations (see also discussion about the DRE ambassadors programme in the previous section). People felt that 'lack of awareness' and the idea of communities as 'hard to reach' could no longer be used as excuses. Instead, the focus should be on the lack of commitment and will to develop and nurture relationships and how these can be overcome.

Some key issues emerged as pertinent in the reflections about the continued lack of engagement. The first was the shift to a 'single equalities' mode of working. Towards the end of the DRE programme and in keeping with the Equality Act 2010, there was a clear steer in policy towards a broader equalities agenda,



and this is carried through in the new mental health strategy. While the benefits of working across equality issues were acknowledged, this should not be at the expense of neglecting key issues for communities.

*“The equalities agenda was being set with BME users having no say in it. Look at the mess created by trying to turn DRE ambassadors into ‘equalities’ ambassadors! People came because they were interested and committed to a cause – improving race equality in mental health. This move to single equalities had no context and many of those who were asked to do this had no expertise. This is exactly what meaningless involvement looks like – let’s shuffle around because someone up there has come up with a new idea...”*

Echoing the views of black and minority ethnic service users in recent studies and consultations (Kalathil 2011, Afiya Trust 2010), there was a view that this should not be unthinking reactions to changing political agendas or at the expense of those most marginalised within and outside services.

*“...whilst it certainly is important to recognise that people are whole people and, in that sense, equalities needs looking at comprehensively, the government’s focus appears to have detracted from an in-depth look at racist attitudes and their impact.”*

‘Intersectionality’<sup>7</sup>, the idea that oppression in society – racism, sexism, homophobia etc. – interrelates or intersects between different aspects that constitute one’s personal and cultural contexts and social relationships, was acknowledged as a more productive way of dealing with inequalities. There is more work to do around this in mental health in general, ensuring that people are treated holistically, and in user involvement initiatives.

The second issue was the impact of cuts in public funding and resources on black and minority ethnic community and voluntary sector

organisations and their role in supporting and sustaining user involvement activities and opportunities. The 2008 report recommended that supporting local organisations through sustainable resources to build their capacity and autonomy should be a key priority to make meaningful user involvement a reality. The review responses show that it is precisely such local, small organisations and groups that are adversely affected by cuts.

*“The government’s ‘big society’ agenda and localism sounds fine but what is really going down? We said support local structures but they are the ones that are being cut. What’s local work without support?!”*

*“One recommendation [in the 2008 report] that stands out is ‘support at the local level’, which has clearly been cut right back in general, and I think BME groups have suffered likewise.”*

*“People are fighting through local groupings and organising, but for those who need more support to get involved, local advocacy is not there anymore and without it, no decent services or opportunities.”*

Again, these views echo recent studies. While the impact of cuts on mental health specific black and minority ethnic organisations is yet to emerge coherently, the broader impact is already established, with one study showing that 45 per cent of all black and minority ethnic voluntary sector groups had faced funding cuts from local authorities, in addition to 61 per cent who faced cuts in government funding, other grant making trusts and the Big Lottery, even as 77 per cent of the sector had experienced a sharp rise in requests for services as people feel increasingly vulnerable (CEMVO 2010).

## **The 2008 recommendations in the current context**

The overall feeling emerging from the reflections is that the political will and the policy context ensuring black and minority ethnic mental health service user involvement were weaker now compared to when the consultations that led to the 2008 recommendations took place. Despite the increasing visibility and strength of user-led groups generally and those from black and minority ethnic backgrounds in particular, the resources and structures to sustain them are diminishing. In this context, partnership working across all user/survivor groups and

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7. Intersectionality is a feminist sociological concept, developed by black feminists like Kimberlé Crenshaw and Patricia Hill Collins. The term, originating in a critique of 1960s and 70s mainstream feminism’s focus on gender as the primary defining factor of women’s oppression, refers to how forms of oppression shape and are shaped by one another, and that subordination and inequality can only be understood by studying these inter-linkages. See Crenshaw (1989). For more information, see [www.intersectionality.org](http://www.intersectionality.org) [Accessed 11/10/11]

between user-led and non user-led groups was even more important in continuing to challenge racism and discrimination in user spaces within and outside mental health services and in influencing decisions about our mental health care.

The 2008 report made two sets of recommendations; one, aiming to influence black and minority ethnic mental health service user involvement in general, and two, for developing partnership working between NSUN and Catch-a-Fiya. As is evident from the discussion above, the problems remain the same and the possibilities, while weakened by the current policy context, are also stronger given the increasing voice and organisation within communities. The broader recommendations are as pertinent today as they were three years ago and are there to guide groups, organisations and services wanting to develop partnerships across ethnic and cultural boundaries for better mental health for all.

In the next chapter we review NSUN's progress in taking the recommendations forward.

# From recommendations to action: work since 2009

One of the key findings from *Dancing to our own tunes* was that there was a need to establish clear structures and values for developing partnership working between generic and black and minority ethnic user/survivor organisations. The report recommended setting up a steering group made up of NSUN and Catch-a-fiya members to:

- strengthen partnership working, promoting co-ownership of the partnership
- produce an action plan and structures to take this partnership forward
- define clear structures that will support people to work effectively, sustain their energy and prevent burn-out

At an event on 8th July 2009, a group of service users and survivors volunteered to form a steering group to take this work forward. Adopting the name TOOTS (To Our Own Tunes) group, they were tasked with setting out ways for NSUN and The Afiya Trust, through Catch-a-fiya, to work in partnership and, more generally, to develop guidelines for partnership working between generic and black and minority ethnic user/survivor-led organisations. NSUN invested £15,000 to take this work forward and commissioned Catch-a-fiya to lead the work. (Please see Appendix 2 for membership of TOOTS group).

## The charter and guidelines

The first task that the TOOTS group took on was to develop a charter and guidelines for partnership working. The 2008 report had identified several barriers to partnership working and involvement. Key among these were:

- discriminatory experiences, including racism and coercive and punitive care, which discouraged people from participating in involvement activities, unless there was willingness and space to discuss these journeys
- experience of racism within user involvement initiatives and user groups, and the keenly felt pressure to separate racial, ethnic and cultural identities from that of a service user/survivor
- power hierarchies within involvement structures and lack of role in setting the agenda and decision making

- lack of adequate payment, support and information

- lack of evidence that people's life situations and experiences within mental health services were changing despite years of involvement

The perception that black and minority ethnic mental health service users/survivors were 'hard to reach' often had, at its base, a mutual distrust that arose from these barriers. Recognising this, a main aim of the charter is to combat the stigma and discrimination against and fear about these communities and service users/survivors from these backgrounds, and to help foster a robust and candid environment of trust. The charter is a set of fundamental principles or values, and aims to help local and national organisations to identify and build upon the strengths and opportunities for developing innovative ways of partnership working.

## The TOOTS Charter

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Partnership working with black and minority ethnic service user/survivor-led organisations involves the following:

- showing a positive and enabling attitude to black and minority ethnic service user/survivor organisations
- acknowledging the discriminatory experiences that people from black and minority ethnic communities face within society, mental health services and within generic user involvement initiatives
- recognising the role of these experiences in making individuals experts in their own right and in informing the nature of partnership working and the solutions to apparent challenges
- empowering them to ascertain that there is confidence in them
- making genuine use of their knowledge, experiences and skills, one which stems from a fundamental value for them
- creating a work environment that ensures mutual listening, hearing and understanding
- ensuring that the partnership organisations have all the necessary information to work together
- ensuring that there is openness and honesty within the relationship that will foster a competent and productive partnership
- treating each other with respect and dignity, with outcomes that benefit all involved
- supporting each other to achieve goals
- having faith in each partner's ability to do the job to the standard required
- providing non-judgemental and proactive support so as to enable each partner to work in their own ways to achieve their aims

## The TOOTS Guidelines

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### Values

- Commitment from all partners to support race equality and changing discriminatory organisational practices
- Mutual respect
- Open mindedness towards cultural differences and diversity in ways of working
- Honesty and openness
- Equality and fairness and a recognition that organisations may be unequal in the power they have
- Sensitivity in language and actions, acknowledging different ways of expressing and doing things

### Setting up partnerships

- Establish a shared vision
- Ensure equality in partnership, acknowledging knowledge and expertise
- Be democratic in leadership and decision making
- Agree on clear roles
- Have clear and realistic expectations
- Identify development needs of partner organisations and individuals involved

### Management

- Share responsibilities, making good use of capabilities
- Ensure accountability
- Share information continually
- Share learning and good practice
- Acknowledge successes and identify difficulties and find solutions
- Conduct regular reviews of the partnership
- Provide on-going support to address race equality issues
- Provide independent support to those who manage the partnership

### Good practice

- Agree quality assurance standards for the partnership
- Find creative and imaginative ways of addressing needs and concerns of individuals that may be different from generic organisational practices
- Be flexible, be prepared for change and difference

Following on from these principles, the guidelines elaborate what the charter would mean in practice and how to facilitate partnership working. The full text of the guidelines is available in Appendix 1. These are values and practices that should underline all good partnerships. What the TOOTS charter and guidelines emphasise is the importance of acknowledging and working with diversity and difference: that there is more than one way of doing things and that people's knowledge and skills are rooted in their personal, cultural and communal experiences. But most importantly, they help organisations focus on race equality and the importance of incorporating a genuine commitment to addressing race equality by being open to questioning and changing organisational practices that may seem absolute and immutable.

## Action plan for partnership working

Having established the charter and guidelines, the TOOTS group set out to outline an action plan for partnership working. The strategic aims of the action plan are:

- to take forward the recommendations of *Dancing to our own tunes* report
- to create an effective partnership between NSUN and Catch-a-fiya
- to provide a model which others might find useful for partnership working between generic and black and minority ethnic user/survivor-led groups

The action plan has two stages. The first stage focuses on the following actions, aimed at establishing the partnership.

- 1) Initiate an independent impact assessment (IA): the IA will look at the capacity and skills of the partner organisations and the impact the partnership will have on the organisation's overall work.
- 2) Review current initiatives and policies: the broader policy developments in mental health generally, in user involvement and in race equality initiatives in mental health will have an impact on any work that the partnership undertakes. These will need to be reviewed and assessed.
- 3) Implement findings from the IA: may involve awareness raising sessions, training, skills development etc. and addressing infrastructure, personnel, equipment and technology needs.

- 4) Establish monitoring structures: regular monitoring of the partnership's work will ensure identifying successes and challenges and help solve problems as they arise.
- 5) Collate and analyse membership databases: this would mean working more proactively to increase membership from under-represented communities; understanding the reasons for underrepresentation and working to address them. Also helps identify the skills and knowledge already available to the organisations through their membership.

The table overleaf sets out the progress made by NSUN and The Afiya Trust in taking the action plan forward. The second stage of the action plan involves developing the work plan for the partnership. The work plan will be based on the ideas that emerged from TOOTS group meetings, the 2008 report, findings from the IA and further consultations with the members of the organisations. A formal partnership agreement is yet to be signed off by NSUN and The Afiya Trust, the organisation that hosts Catch-a-Fiya. However, the learning from the 2008 report, the TOOTS group's work and the informal and on-going partnership between the organisations have influenced some of the work undertaken by the two organisations over the last three years.

## BME user engagement within NSUN

Following consultations with staff, trustees and the network membership in 2009, NSUN published its strategic plan 2011–2016. One of the five strategic themes that inform the work plan for the next five years is 'engagement and capacity building', with special attention given to black and minority ethnic communities (NSUN 2011: p4). The review and reprint of *Dancing to our own tunes* is a strategic priority helping to achieve the objective of setting up formal and inclusive networks in all nine English regions. Another strategic theme informing the work plan for the next five years is 'partnership working'. A key objective under this is "providing a model for partnership working between generic and black and minority ethnic service user/survivor groups" by taking the recommendations from the report forward (p8).

Fifty per cent of NSUN's staff and two of the seven trustees identify as belonging to a minority ethnic community. NSUN has also adopted a strategy of pro-active recruitment



## Progress made in Action Plan stage 1: establishing the partnership

Actions	Progress
<p><b>Governance</b> Initiate an independent impact assessment. This should relate to the organisations' capacity and skills to undertake the partnership, and the impact of the partnership on their overall work.</p> <p>Review current initiatives and policies in the broader and BME specific mental health fields and assess their relevance for the partnership.</p> <p>Implement findings from the impact assessment.</p> <p>Establish monitoring and evaluation mechanisms to assess the success of the partnership.</p>	<p>NSUN is currently in the process of identifying external consultants to undertake the impact assessment.</p> <p>The Afiya Trust has commissioned a Social Return on Investment (SROI) assessment of its overall work. This includes a specific focus on user leadership and partnership working. The report of this work is expected by the end of the year. It has also appointed an independent chair for Catch-a-Fiya.</p> <p>Both organisations work together at the Ministerial Advisory Group and the Equalities Advisory Group for mental health.</p> <p>Work undertaken in relation to the National Involvement Partnership (NSUN) and the consultations on recent health, social care and public health white papers (Afiya) feed into continuing reviews of the field.</p> <p>To be done.</p> <p>The SROI assessment currently underway at Afiya has produced a structure for on-going evaluation and monitoring and staff have received training in using this structure.</p>
<p><b>Infrastructure</b> Implement infrastructure needs that may be identified through the impact assessment.</p>	<p>To be done.</p>
<p><b>Membership</b> Collate and organise demographic statistics of NSUN and Catch-a-Fiya membership.</p> <p>Increase membership from diverse BME communities in NSUN.</p> <p>Increase membership from under-represented minority ethnic communities in Catch-a-Fiya.</p>	<p>Membership forms have been revised and demographics sections added. NSUN has appointed a new information officer who will start collating this information.</p> <p>Proactive recruitment of participants from BME groups is now part of NSUN's regular practice.</p> <p>This is one of the specific remits for the independent chair.</p>
<p><b>Mapping BME service user groups &amp; individuals</b></p> <p>Maintain an up-to-date database of the above.</p> <p>Implement any specific personnel, equipment and technology needs identified through the impact assessment.</p>	<p>This will be part of the newly appointed information officer's work plan and will be reviewed against existing membership.</p> <p>To be done.</p>
<p><b>Training</b> Assess and implement training needs for both partners identified through the impact assessment.</p>	<p>To be done.</p>

and engagement with black and minority ethnic communities in its activities. For example, 60 per cent of those involved in local commissioning consultations, 35 per cent of groups involved in the South East Champions programme and 30 per cent of those involved in the Talk for Health initiative are from black and minority ethnic communities.

The commitment to developing partnerships with black and minority ethnic service user/survivor groups, clearly stated in the strategic plan, is evidenced in the corresponding increase in the number of black and minority ethnic service users/survivors now fully engaged with NSUN activities as described above. It would be useful for NSUN's future work to get more clarity about how these service user/survivor groups perceive NSUN's role in supporting users and survivors and their success in engaging people from black and minority ethnic communities. To achieve this clarity, the impact assessment proposed in the action plan (see previous section) should include an analysis of the database followed by a survey of service users from black and minority ethnic communities and groups representing them.

### **Mental health service user leadership within The Afiya Trust**

The Afiya Trust works across health conditions and social care issues to reduce health inequalities for racialised individuals. Mental health is one of the key priorities in its work, and Afiya has a track record of supporting user involvement across its work programmes. It is this dedication that led to the formation of Catch-a-Fiya as a specific forum for BME user/survivor leadership in 2006. The Afiya Trust continues to support user involvement and leadership as is evident from its manifesto, *Achieving equality in health and social care: a framework for action* (2010).

When the 2008 report was published, Catch-a-Fiya was the only national network of black and minority ethnic service users/survivors, with dedicated resources and staff and strong regional presence in at least two English regions (Lemma 2009). Dedicated funding for the network came to an end in 2009. Repeated attempts to find more money to keep the network functioning as it did at its best have been unsuccessful. The Afiya Trust found resources to keep it going, albeit in a lower key, by continuing to fund the co-ordinator's post for a further 18 months. This

was also supported by funding from NSUN to take the TOOTS group's work forward.

Currently, Catch-a-Fiya is coordinated by a part-time independent chair, who is working to re-establish the network as a coherent voice of BME service users/survivors. A new steering group, nominated by the members and representing all English regions, is currently being brought together to support the independent chair.

Despite the lack of dedicated funding, The Afiya Trust has continued to support and build the capacity of Catch-a-Fiya members by accessing funding wherever possible, most recently through the work and recovery project. It has also continued to consult with the members on responses to policy like New Horizons and the public health white paper. It also shares information, good practice and opportunities for involvement through e-bulletins.

This review found that the commitment within the organisation to develop mental health service user leadership was not under question. However, the documents analysed for this review did not show evidence of Catch-a-Fiya providing or enabling active leadership in developing policy positions and priorities, campaigns, research and training, service evaluations and audits, peer support as it used to when it was a fully funded network<sup>6</sup>.

The reflections of Catch-a-Fiya members contacted for this review support this conclusion and point to several possible reasons for the apparent 'decline' of mental health service user leadership within The Afiya Trust. One view is that the general decline in the focus on mental health service user involvement generally and on race equality specifically, discussed in the previous chapter, are reflected in the lack of interest in funding a network like Catch-a-Fiya or supporting its work. The second view is that there was not enough service users/survivors involved in decision making roles within Afiya. In the past, the coordinator/manager of Catch-a-Fiya provided such a central role, both within the organisations and outside by representing The Afiya Trust in contexts where policy decisions were being made.

Actively promoting and seeking the expertise and leadership mental health service users within a non user-led organisation working

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6. See Kalathil (2009) for Catch-a-Fiya's achievements during 2006–2009 and Lemma (2009) for the report of the evaluation of Catch-a-Fiya's work.

across health and social care issues require rigorous organisational structures and policies. It will need to develop robust internal policies for mental health service user leadership, recruiting and supporting service user staff, or strategic plans for ensuring user/survivor leadership within its overall principles and policies if the commitment within the organisation is to be turned into practice. A programme of staff and trustee training in the principles and development of mental health service user leadership is called for, utilising the skills and knowledge within Catch-a-Fiya membership to deliver this training programme. It is also recommended that the TOOTS action plan, the recommendations from the 2008 report and the work priorities set out in the end of project document *Creating a cohesive voice* (Kalathil 2009) are brought together to put in place a strategic plan for developing Catch-a-Fiya further.

## Influencing the sector: National Involvement Partnership

The National Involvement Partnership (NIP) emerged from a contract awarded by the now disbanded National Mental Health Development Unit (NMH DU). NMH DU wanted to assess user/carer involvement in its work programmes, identify gaps and find ways working better with service users and carers. NSUN led a consortium of organisations, including The Afiya Trust and Catch-a-Fiya<sup>7</sup>. Despite the closure of NMH DU, NIP has developed into a feasible infrastructure for the involvement of service users and carers in mental health policy development.

In 2010, a scoping report of NMH DU's user/carer involvement was prepared (Faulkner 2009). This work developed a model for involvement – the Purpose, Presence, Process and Impact (PPPI) model<sup>8</sup>. This model presents an accessible way of describing and monitoring user involvement:

- Purpose: having a clear purpose for involvement enables everyone to understand their role and avoids the risk of tokenism and involvement for its own sake.

- Presence: the number of service users and carers involved; their characteristics in relation to the project/programme (e.g. age, gender, ethnicity, specific (service/diagnosis/treatment) experience, and so on).

- Process: at what level in the project/programme are service users and carers involved: what role(s) are they occupying? How is the process of involvement experienced by all? Is the programme/workstream engaging good practice guidelines (e.g. from *Making a Real Difference* or MARD) to involve people?

- Impact: what impact – if any – are service users or carers having on the programme or workstream?

The PPPI model shares several characteristics with the TOOTS charter and guidelines for partnership working, including the need for clear statement of purpose, acknowledging the diversity of experiences that service users/survivors might bring to the table, monitoring progress and so on. Specifically, the scoping report makes a recommendation that “each programme and workstream seeks to include service users and carers from BME communities as a priority” and that this would include paying attention to different methods of being involved (Faulkner 2009, p24).

The Mental Health Foundation evaluated NIP's work using the PPPI model to assess service user and carer involvement within NMH DU and the effectiveness of NIP in facilitating service user and carer involvement (Robotham and Ackerman 2011). The evaluation report concludes that “within the PPPI framework, NIP appears to have the potential to facilitate involvement practices within organisations such as NMH DU” (p22) but that making sure there was a diverse, representational presence within projects and programmes was challenging to both NMH DU and NIP:

*“NIP itself had difficulty addressing diversity, and their initial promotional events were criticised on these grounds. Ensuring diversity for involvement across the different strands within NMH DU proved challenging, but there was positive feedback about how NIP had worked to ensure representation from a diverse spread of people” (p22).*

7. The members of the consortium included, in addition to NSUN and The Afiya Trust, Attend, Equalities National Council, Together, Mental Health Foundation and Social Perspectives Network. For more details, see <http://www.nsun.org.uk/about-us/national-involvementpartnership/> [Accessed 29/09/2011]

8. See [http://www.nsun.org.uk/modules/downloadable\\_files/assets/baseline-standards-handoutmay-2011.pdf](http://www.nsun.org.uk/modules/downloadable_files/assets/baseline-standards-handoutmay-2011.pdf) for a briefing on this model. [Accessed 29/09/2011]



Ensuring diversity is obviously not just about increasing the involvement of service users and survivors from black and minority ethnic communities. But a further comment in the evaluation report highlights the significance of this specific issue. This relates to the lack of response to the evaluation surveys from people from black and minority ethnic communities, pointing, the authors felt, to a “lack of diversity in service user involvement projects per se” (p23).

The TOOTS charter and guidelines provide NIP with a clear structure to develop the involvement of service users and carers from black and minority ethnic communities. It is recommended that the PPPI model is further developed to incorporate the TOOTS charter and guidelines so that black and minority ethnic user/carer involvement (and by extension, the involvement of other diverse and often under-represented groups) does not remain an addendum to the structures and standards for involvement.

## Influencing commissioning: Joint Commissioning Panel – Mental Health

The Joint Commissioning Panel for Mental Health (JCP-MH) is a new collaboration between leading organisations with an interest in mental health and learning disabilities. Its objectives include:

- publishing briefings on the key values and principles for effective mental health commissioning
- providing practical guidance and a framework for mental health commissioning
- supporting commissioners in commissioning mental health care that delivers the best possible outcomes for health and wellbeing
- developing guidance for best practice commissioning in areas where disparities in outcomes exist
- bringing together patients, service users, clinicians, commissioners, managers and others to deliver the best possible commissioning for mental health and wellbeing

Initially, the panel was made up of the Royal College of General Practitioners, the Royal College of Psychiatrists, the NHS Confederation, Association of the Directors of Adult Social Care (ADASS), the National Involvement Partnership, NSUN, Mind, Rethink,

the British Psychological Society and HFMA MH Finance.

As a member of the JCP-MH, NSUN raised the issue of involvement from black and minority ethnic communities on the panel and has been working to counter the view that since the panel cannot include representatives of all protected characteristics under the Equality Act, representation based on race and ethnicity should also be avoided. *Dancing to our own tunes* report was used as evidence to emphasise the importance of involving black and minority ethnic communities, along with the analysis of the impact of the new mental health strategy on equality. At its fourth meeting (18th March 2011), an action point to invite an organisation representing black and minority ethnic communities was agreed.

NSUN wrote an ‘opinion piece’<sup>9</sup> in consultation with The Afiya Trust, Catch-a- Fiya and Mind and made the following recommendations to the JCP-MH:

- make a formal approach to The Afiya Trust from the chair of JCP-MH to advice on black and minority ethnic mental health issues
- an ‘Equalities Reference/Advisory Network’ that advises all Department of Health boards and links with other equalities initiatives is set up
- develop good involvement practice modelled at a national level which will inform guidance at local level
- set up a delivery budget for wider involvement/engagement activities

These recommendations were made with the view that national involvement will be informed and influenced by the existing local and regional structures that organisations represented on the panel are linked to. The proposal is also to develop standards of involvement based on the PPPI model. It will be vital, as discussed in the previous section, the PPPI model is developed to incorporate the TOOTS charter and guidelines so that the standards developed based on this model has race equality at its heart and not as an add on.

As a direct outcome of this intervention, The Afiya Trust has now been officially invited to join the panel as a member. A proposal to include equalities and involvement in its wider business plan is currently awaiting decision.

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9. The ‘opinion piece’, written following a focus group in April 2011, is available from NSUN.

# Conclusions and observations

This review is based on the personal reflections of service users/survivors who contributed to the *Dancing to our own tunes* report, members of the group set up to work on its recommendations, and external stakeholders, along with findings from the analysis of policy and procedural documents. It is, thus, limited in scope and in verifiability. Nevertheless, it provides a picture of the current context of black and minority ethnic mental health service user involvement. It also provides a picture of the progress made by NSUN and The Afiya Trust in taking forward the recommendations made by the 2008 report.

Based on the above, the following observations for future work are made:

- 1) While the idea and concept of user involvement is well established, with many user-led groups “*dancing to their own tunes*,” there is still much work to be done to ensure that the race equality agenda remains active and to continue to fight the adverse experiences of service users from black and minority ethnic communities both within and outside mental health services.
- 2) The findings and recommendations in the 2008 report are as relevant today as they were when the consultations were done. There is a renewed onus on national organisations with resources and capacity to support local groups to ensure that the momentum built over the years is not destroyed by funding cuts and policy shifts.
- 3) While the work done so far is commendable, both NSUN and The Afiya Trust have more to do to take the recommendations forward and to ensure that the meaning of black and minority ethnic mental health service user involvement and leadership, consolidated in the 2008 report, is fully informing their own work and their work in partnership.

## NSUN could:

- do more work to disseminate the TOOTS charter and guidelines widely
- ensure that these are an integral part of ‘generic’ user involvement models, specifically by reworking the PPPI model to incorporate the TOOTS charter and guidelines

- promote this reworked model as involvement standard through the decision making forums they are part of along with The Afiya Trust (for example, the JCP-MH) The Afiya Trust could:

- focus on a programme of work, including staff training, to embed the principles and practice of mental health service user leadership within its strategic plans, organisational policies and everyday work
  - make use of the expertise available within the Catch-a-Fiya network to inform organisational strategies and staff training
  - review the legacy documents of Catch-a-Fiya and work with the new steering group and independent chair to ensure that the learning from its work is not lost or reinvented
  - along with NSUN, work to promote involvement standards based on the TOOTS charter and guidelines and the PPPI model
- 4) Finally, an action plan to start work on the remaining recommendations of the 2008 report needs to be developed with the two organisations working in partnership.

***“The message is clear – consultation is not involvement. If there has to be meaningful involvement of service users/ survivors from black and minority ethnic communities in mainstream initiatives, there has to be structural changes in hierarchies, ways of working, assumptions, power structures within institutions, resource allocation, the location of decision making, and the way people are treated within mental health services and outside them.”***

***Dancing to our own tunes, 2008***

## **PART 2**

# ***Dancing to our own tunes: reassessing black and minority ethnic mental health service user involvement***

(Report of the 2008 consultation)



### **Jayasree Kalathil**

With contributions from Hanif Bobat, Michelle Bhalroo, Patricia Chambers, David Crepaz-Keay, Chandra Fowler, Matt Gregory, Paul Grey, Raza Griffiths, Andrew Hughes, Carol Jenkin, Theresa Kiyota Rahman, Dominic Makuvachuma-Walker, Terry Simpson, Premila Trivedi, Jan Wallcraft

# Introduction

This report presents the findings from a consultation exploring the involvement of service users/survivors from black and minority ethnic communities in mainstream user involvement initiatives in mental health. Funded by the National Survivor User Network and commissioned in partnership with the Catch-a-Fiya Network, this work is the first of its kind which has been fully funded, developed and undertaken by service users and survivors.

Engaging people who use mental health services in developing those services, a process generally known as ‘service user involvement,’ is now an intrinsic part of policy (DH 1999; 2005; NIMHE 2003). As a result, user involvement and participation initiatives are now on the agenda of most mental health trusts. The acknowledgement of the centrality of user involvement in bringing about changes in service delivery has come as a result of several years of campaigning from the mental health movement and service user/survivor groups. It is based on the idea that service users and survivors are experts in their own experiences and that self-organisation and self-determination are crucial in their journey to recovery.

User involvement is not only about participation in policy-driven, organisational initiatives. It is also about involving oneself in peer groups, for personal support and/or political campaign. In recent years, a body of knowledge has begun to develop, looking at involvement or participation in different contexts and what that means for people who use services (Carr 2004; HASCAS 2005; Wallcraft 2003; Crawford *et al.* 2003; Branfield *et al.* 2006). While user involvement is generally seen as enabling, some groups, for example, people from black and minority ethnic communities, are not as ‘involved’ as others in mainstream user involvement initiatives. While several reasons – ranging from racism within involvement activities and spaces to people consciously choosing to opt out of mainstream initiatives – have been posited for this perceived ‘under representation’ of service users and survivors from black and minority ethnic communities, only a handful of studies have explored the issues involved in any detail (for example, Begum 2006; Blakey 2005; Trivedi 2001, 2008).

The National Survivor User Network (NSUN) was launched with the mission to “develop

networking, which will engage, support and reflect the diversity of mental health service users and survivors across England.” One of its core aims is to facilitate and enable the widest range of survivors and service users to have a voice in informing and influencing local, regional and national developments in mental health. Catch-a-Fiya was set up by The Afiya Trust as a user/survivor-controlled forum, with an overall vision of motivating and supporting service users and survivors from black and minority ethnic communities to “learn, teach and grow.” Catch-a-Fiya aims to offer opportunities to service users/survivors for reflection and dialogue, find a common purpose and think creatively about what future services might look like. It is with these overall aims in mind that NSUN and Catch-a-Fiya decided to explore the nature of participation of black and minority ethnic service users and survivors in user involvement initiatives in mental health.

## A word about the report

While the impetus for the project has come from the need to explore how to increase collaborations between mainstream user networks and service users/survivors from black and minority ethnic communities, the report has lessons for everyone who is interested in critically reflecting on the current scene of service user involvement. The chapter titled ‘Effective involvement: recommendations for change’ has a series of recommendations that everyone who is interested in meaningfully involving service users/survivors would find useful. The recommendations in the chapter, ‘Looking to the future’, are specifically aimed at increasing partnership working between NSUN and Catch-a-Fiya, but are of relevance to those wanting to work with black and minority ethnic organisations and groups. We hope that the report will enable good practice.

The strength of this report lies in the participants’ experiences and how they articulated them. The quotations have not been attributed to anyone in order to preserve anonymity in such a small sample of people. The quotations have been slightly edited in some places to enable clarity and conciseness. References are made throughout the report to existing scholarship in the area where relevant. These have been clearly signposted.

# An outline of the work

## The aims

The main focus of this project was to explore the barriers to and solutions for meaningful involvement, some of them already familiar, through the experiential knowledge of service users and survivors who have worked in various involvement initiatives and contexts. The objective was not to access representational data through a large research process, but to concentrate on lived experience and learn from that. The main aims of the project were:

- to develop recommendations for good practice in increasing the involvement of service users/survivors from black and minority ethnic backgrounds in mainstream service user initiatives; and
- to describe an outline for a programme of work to be undertaken by NSUN to stimulate positive change in this area.

## The participants

The service users and survivors who participated in this project were recruited through NSUN and Catch-a-Fiya networks. They brought together a wide range of skills – in setting up and running user groups, advocacy and peer support, personal and community development, research, training, use of art and media. Together they represent a range of experiences – of working as user involvement workers within statutory and voluntary sector organisations, in local user groups, mainstream national bodies, black and minority ethnic specific groups, various advisory and steering groups, and in research and evaluation projects. Some had over twenty years of experience of working to improve mental health services, while others were comparatively new to active involvement. Geographically, the participants were from London, West Midlands, East Midlands, West Yorkshire and the South West. Overall 15 people took part in the project.

## The process

### **A day-long meeting with service users/ survivors from black and minority ethnic backgrounds**

The day was organised into three sessions. In session one, participants discussed the barriers to involvement in mainstream service user movements and generic user groups. Session two looked at the barriers faced when involving in advisory, consultation and participation initiatives set up by service providers, professionals, mainstream voluntary sector organisations and policy makers. Session three focused on strategies to overcome these barriers.

### **A half-day meeting with service users and survivors from white British backgrounds**

In the first session, the participants discussed the efforts made to increase black and minority ethnic service user involvement, based on their experiences of working within mainstream initiatives. The focus was on what worked and what didn't and why. In the second session, they continued to explore how to increase black and minority ethnic service user involvement.

### **One-to-one interviews**

Three one-to-one interviews were conducted with people who have had a substantial amount of experience in working in a variety of involvement initiatives. Two were from black and minority ethnic backgrounds. A semi-formal topic guide was used to steer the interview, but as is expected in research that is designed to focus on the service user's experience, the thrust of the interview was determined by what the interviewee felt were the crucial points to discuss. The number of interviews was restricted to three due to limited resources.

## Post-consultation workshop

All participants were invited to a post consultation workshop where the main findings from the group meetings and interviews were presented. The group worked together to formulate the recommendations to stimulate change in the way mainstream user groups can work meaningfully with service users



and survivors from black and minority ethnic communities. The group then discussed the key areas of work that could be taken forward through a partnership between NSUN and Catch-a-Fiya.

## The questions

As suggested earlier, there have been very few studies concentrating on the experiences of service users and survivors from black and minority ethnic communities in user involvement. The general perception is that there is an 'under-representation' of service users/survivors from black and minority ethnic communities in mainstream involvement initiatives. Several reasons have been attributed to this perceived underrepresentation. Significant among these is the fact that the processes of involvement and participation are not sensitive or adapted to the needs of service users from black and minority ethnic backgrounds. Nasa Begum (2006) analysed the myths surrounding black and minority ethnic service user involvement in social care and suggested that, while black and minority ethnic communities have a long history of self-help and direct experience, their participation in social care initiatives will only be meaningful if their involvement moves from being purely consultative to one that is real and constructive.

Based on her substantial experience of being involved in various user involvement activities, Premila Trivedi (2001, 2008) has written about the hierarchical nature of these processes, and the power plays and racism within both policy-driven initiatives and mainstream mental health movements. She argues that user involvement will become a meaningful reality only if the damage done to individuals within mental health systems is acknowledged, and the roles and power relations between users and mental health professionals in involvement settings are evaluated.

A collaborative project between the International Centre for Participation Studies (University of Bradford) and Sharing Voices (Bradford) found that one of the biggest barriers was the belief among communities that the health services would not listen, and that change would not follow (2005). This study also commented on the fact that unless user involvement spaces provide opportunities to explore the negative and difficult experiences that people from black and minority ethnic communities have faced, it is likely that people will not engage.

Another significant factor has been that black service users/survivors have consciously chosen to opt out of mainstream activities and set up their own involvement initiatives. The reasons for this range from the experience of racism within mainstream spaces to the conviction that health needs are tied with identity politics and cannot be adequately represented through mainstream initiatives. Premila Trivedi and members of SIMBA (Share in Maudsley Action) wrote that their efforts to raise awareness and improve services for black people were better achieved through a black group that worked on their own terms and defined their involvement (Trivedi et al. 2002).

We wanted to place our conversations within this context. The facilitation guides for the group meetings were prepared noting the main points raised by some of the works cited above.

## The analysis

The group meetings and interviews were recorded and transcribed. The transcripts were analysed by the researcher to pull out emerging themes. The summary report was circulated to everyone who took part in the consultation. The post-consultation workshop allowed time for participants to discuss and comment on this summary report and make suggestions for writing the final report. The draft final report was also circulated to the participants and suggestions and changes incorporated before finalising the report.

# Redefining involvement

The term 'user involvement' is generally understood to mean specific activities involving service users, often driven by policy, and often defined by the organisation setting up those activities. The strongest message from the consultation was that there was a need to re-examine this understanding of user involvement. Participants, especially those from black and minority ethnic communities, felt that the mainstream definition of involvement did not appeal to people from black and minority ethnic communities. Several reasons were cited for this.

Some of the ethnic minority communities continue to be over-represented in rates of admission into in-patient care, of sectioning under the Mental Health Act, of coercive treatment, of diagnoses of schizophrenia and so on.<sup>10</sup> The fact of their overrepresentation in services shows that they are very 'involved' in mental health services, albeit against their wishes. Many policy guidelines declare that the point about involvement is in allowing service users to contribute in their own care and in planning services (DH 1998) and in giving people "more say" or "a stronger voice" (DH 2006a, DH 2006b). However, historically, those from black and minority ethnic communities who have been 'involved' in mental health services have not been listened to.

The mainstream definition of service user involvement, it was felt, excluded a lot of the work that people were doing on the ground, within their communities.

*"There are a lot of black survivor groups within localities that are getting on and rolling their sleeves up and doing the work. Our task should be to try and coordinate and pull together some of the activity that's going on and look at the sheer volume and scale at which localities are galvanised already in getting on with work."*

In this sense, rather than thinking about an under-representation of people from black and minority ethnic communities in user involvement initiatives, we need to start thinking of ways in which to support and nurture work that people are doing within their communities and localities.

A starting point for this project was the acceptance that service users and survivors from black and minority ethnic communities had a central role to play in changing mental health service delivery and in influencing policy decisions in this area. From this perspective, it seems imperative that the involvement of black and minority ethnic service users/survivors need to be increased. It is common to hear mainstream organisations (and indeed the Department of Health) refer to black and minority ethnic communities as 'hard to reach.'

Participants, especially those from black and minority ethnic communities, felt that 'increasing involvement' seemed to propose the need to ensure more 'black bodies' on committees and steering groups, without examining organisational cultures that viewed marginalised communities as 'hard to reach.' Indeed, the experiences of being involved in this way were overwhelmingly negative.

The message is clear – consultation is not involvement. If there has to be meaningful involvement of service users/survivors from black and minority ethnic communities in mainstream initiatives, there has to be structural changes in hierarchies, ways of working, assumptions, power structures within institutions, resource allocation, the location of decision making, and the way people are treated within mental health services and outside them.

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10. In 2011, we are able to look at the data from the Count Me In census over a period of five years and see how little changes have happened in this area, regardless of the DRE programme's twelve characteristics, three of which were a reduction in the rate of admission of people from BME communities to psychiatric inpatient units, a reduction in the disproportionate rates of compulsory detention of BME service users in inpatient units, a reduction in the use of seclusion in BME groups. See Care Quality Commission (2011).

# Barriers to involvement

## Negative experiences within mental health services

The overall experience of dealing with mental health services has not been a positive one for service users/survivors from black and minority ethnic communities. The fact that some communities, for example the African-Caribbean community, have been disproportionately at the receiving end of coercive and punitive care is well documented. Participants felt that many people from black and minority ethnic communities come out of services in a situation where they are not in a good place to be particularly motivated to involve themselves in changing services. Partly, it was felt, this was because of the discriminatory way in which psychiatric services have treated people from some communities. Many people may feel the need to leave damaging experiences behind. Participants felt that it was important to understand this need and where it is coming from. As one participant put it:

*“Why would we want to get involved anyway considering that we’ve been so ill-treated the whole way through the system, why would we actually want to go back in there? It’s like people just want to completely disengage from that and forget that as actually being part of their life.”*

It was felt that user involvement initiatives did not allow space for discussing these negative experiences. They tend to assume that service users/survivors and services can start working together without addressing the discriminatory practices that continue to influence the way in which services are delivered.

*“Discrimination within psychiatric services means that most likely you’ve got a diagnosis of schizophrenia, you’re on high levels of medication and you are less likely to get involved full stop. Unless you start addressing some of those issues then a group of people that are experiencing the worst of psychiatry are never going to be in a position to be actively involved in changing that.”*

This point was made in an earlier community consultation undertaken by Sharing Voices and the International Centre for Participation Studies (2005). Heather Blakey, reporting on this consultation, noted that the Department of Health, in its statement about patient and

public involvement, posits an ideal situation where participants of these forums may rarely need to be adversarial, and will be positive and collaborative. But, she argues, unless these spaces explored the emotional journeys, the negative and difficult experiences that people have been through, it is less likely that people will feel able to engage (Blakey 2006, 24).

While some communities are overrepresented within services, other sections of black and minority ethnic communities were not receiving adequate attention. Some participants felt that this meant opportunities for involvement were not available for those who might want to get involved through support groups or user groups.

*“You’ve also got communities and groups who are just ignored by service. So older Asian women in a lot of places have no services at all, and because they’re not getting services, there’s no locus for involvement, there’s no kind of place where you can naturally gather to get involved with each other or with other people to share that experience.”*

## Everyday issues and survival are priority

User activism and working to change structures and institutions are only possible if one has a stable life and support mechanisms. Many people from black and minority ethnic communities find that having their basic needs met is a big struggle.

*“I think there are lots of issues that people are really struggling with, which are more of a priority to them than user involvement, you know, if they haven’t got their benefits sorted out or decent housing, if they’ve got complex issues with their family or community or whatever, that’s going to be priority before getting involved.”*

Unless there is a change in someone’s life situations, including their mental health, it is less likely that they will be interested in user involvement. This was borne out by the participants’ own experiences – they said that they were able to participate in user involvement initiatives only when they felt stable and supported.



The struggle to fulfil basic needs and access services that many people from black and minority ethnic communities face and how that affects their taking part in user involvement initiatives have been commented on by Nasa Begum (2004) and Premila Trivedi (2008). Begum suggests that this has created a myth about participation not being relevant to black and minority ethnic service users. She argues that while people may be reluctant to participate depending on their experiences and needs, this does not mean that opportunities to participate are not revisited or reviewed as circumstances and experiences change.

Some experiences of involvement in terms of attending user groups have been positive, in that peer support and relationships with other service users/survivors have been useful in gaining confidence and reducing social isolation. However, people felt that there was not enough evidence to show that service-oriented, policy-driven user involvement had been successful in creating change in people's life situations or in the way mental health services treated them.

*"Real power is about having your own finances, having your own identity and all those kinds of things. [With user involvement] people's lives never improve, in the sense of their abilities, management skills, fending for themselves. When you look at things like Breaking the Circles of Fear, when we did the research, people weren't actually talking about user involvement, they were talking about survival."*

## **Racism within involvement initiatives**

The racism that people from black and minority ethnic communities face in society and within mental health services was a reality within user involvement spaces as well. Some black service users/survivors have written about how they felt intimidated and silenced when they raised issues around race in generic involvement initiatives, but had more positive experiences when they refrained from raising these issues (Trivedi 2008, 2001).

Several examples of how racism operated both in the context of service-led, policy driven user involvement initiatives, and within mainstream, generic user groups, were narrated by participants. Some participants spoke of their experience of being invited to

sit on committees that deliberated on policy issues, where they found themselves to be a minority within a minority – these committees had very few service users/survivors on them and very few of these were from black and minority ethnic communities. In this context, it was difficult to raise issues relating to race.

*"In fact I was told on one occasion that if didn't stop talking about race then these very important people on the committee were going to resign and therefore I should shut up. Those kinds of threats were made."*

Such pressures were felt within service-led user involvement spaces as well. Being told that race was not on the agenda was felt as threatening and thwarting.

*"I've been in a couple of jobs now where people have said to me, just openly, oh well you're here as a service user, you're not here as a black person, so don't go on about race really. It's alright for you to bring up user issues but you're not here in that capacity. But look at my skin! I cannot take off my skin and come into this room as a service user."*

The feeling was that one could only talk about issues of race if the initiative was set up solely for that purpose. Race was not seen as part of the overall, general issues that might affect some of the service users using the services. One person felt that this was a reflection of how the society at large treats people from black and minority ethnic communities:

*"As long as you blend in then you can have your say, but if you're going to express yourself as being different..."*

This pressure to separate your identity as a service user/survivor from that of a black person was felt also within generic user groups. Admittedly, the experience varied from group to group and, even within a group, from person to person. In user groups, raising issues related to one's race and identity sometimes generated accusations of creating divisions within the group. The focus was on user/survivor identities; the tendency was to brush over other markers of identity, like that of race.

*"Within the wider user movement – you'd go and talk at a user conference and people would say things like, oh, I don't think we should be making distinctions between black and white, we should remember that old song, "coffee coloured people by the score" and*

*all that stuff. Things like that I found really upsetting because you were talking about issues which were really important and people were just trying to say well actually we're all the same. People would come up to you at meetings or conferences and say to you, no, I don't see you as [a specific ethnicity], I see you as a human being and they think they're being really nice to you, treating you with equality. Well, actually, me being [a specific ethnicity] is an absolutely crucial part of me and if you don't see that then you're not really seeing me."*

Some people spoke about how, in the early days of user activism, they found it difficult to address issues of race within user groups. Part of the reason for this, they felt, was internalised racism and the fear that they would be rejected by the group which, despite all the problems, was seen as a support mechanism. As more and more service users from black and minority ethnic communities became visible, this fear became less and there was hope for other support systems and spaces.

There was some discussion on how deep rooted racist attitudes became apparent even within well-meaning white organisations which would otherwise think of themselves as providing an egalitarian space for all service users. An example was given where, within a generic user group, a problem developed between two black members. The predominantly white group found it difficult to deal with the problem, and seemed to be 'paralysed.'

*"Racism is much bigger and broader than I thought it was, and it's not just about the things that are really overt, but it seems to me that it's very deep rooted in us as white people really. If you do manage to get black people involved in the structure of your organisation, invite them in, then if a problem develops that kind of internalised racist stuff that's not on the surface, it comes out in just not being able to deal with it very well. Or not being able to act in a way that you would if it was two white people who got into a struggle."*

The inability to act when problems develop between members of different ethnic groups within a generic user group, or when there is a situation that is potentially racist, was discussed at length in the mainstream service users' meeting. Some people felt that there was a collusion of race and class in action.

The problem discussed in the example above is, some felt, a result of the middle-class awkwardness around people from black and minority ethnic communities. Within disadvantaged white areas and communities, the problem is one of aggression towards minority communities, where disadvantage, class and race combine to create difficult situations.

The user movement, it was felt, had learned to fight against the discrimination faced by people with psychiatric diagnoses, but it had not been successful in extending that learning to speak up when people were discriminated against because of their race or ethnicity. Racism will keep complicating matters, particularly at times of conflict, unless there is a real commitment not just to have good policies, but to keep learning and challenging ourselves.

*"Dealing with racism isn't just a thing that the people who are subject to racism have to do – it's all of us who have to deal with it. We need to start taking a broader responsibility when we have the opportunity, time, energy and resources to do it."*

## **The stigma within communities**

*"We all have our own issues about stigma, we don't want to come out and talk about it."*

In some cultures, being seen as having a psychiatric problem or diagnosis is a stigma. The way our communities see mental distress has an impact on how or how much an individual service user will associate with user involvement initiatives.

*"The reality is there's so much stigma and discrimination and mental distress is seen as a symptom of failure that one does not want to even engage with it. It is a shame, not only to oneself, but to one's family, to one's community. It's very difficult, I think, to engage with communities and to kind of try and change that perception."*

For some, this is reason enough not to be involved, while for others involvement is an opportunity to change the negative perceptions of mental distress within their communities. But this complexity is not acknowledged within involvement initiatives and there is little support for those who would like to be involved.

*"I experience oppressions from mainstream white society but also from within the community as well. So I feel like I'm constantly*

*beleaguered and kind of under threat, but I do want to challenge that, you know? And I think my involvement with the mental health system really triggered something off and made that more the case, because my experiences were very oppressive within the services, but I didn't necessarily feel that the community was always behind me. So it just feels that I'm neither here nor there, it just feels a little bit like they're multiple oppressions."*

A lot of this stigma, it was felt, was also due to how racialised stereotypes of mental distress are perpetuated. For example, there are any number of white people, often famous, whose madness is presented as a sign of genius; their achievements something to aspire to. Several government sponsored programmes have used these figures as part of their anti-discrimination campaigns. But black people with mental health problems are still presented, in society and in the media, as "big, bad and dangerous."

Some people felt that changing attitudes within our own communities has to be a priority. One person talked about how being seen as a role model was one of the enabling aspect of user involvement work.

*"I've managed to make at least some people think. They actually saw a role model come into the wards, someone who was in the wards now running an organisation, and they could actually see that they could move on as well."*

### **Involvement – whose agenda is it?**

*"It's our involvement but we're still dancing to their tunes."*

One of the biggest barriers in participating in user involvement initiatives was the fact that, in most cases, service users/survivors had no part in setting the agenda. The experience, most often, was that decisions had already been made elsewhere and service users/survivors were only expected to give some feedback which may or may not be considered.

*"It's not our agenda usually. We're trying to fit into the agenda of service providers and very often their agenda is not very honest because a lot of the key agendas these days about choice, social inclusion, recovery, things like that, they nearly always turn out to be about saving money and you only find that out when you get really, really involved in it."*

Some people felt that white mainstream user groups have also been guilty of setting agendas and expecting black and minority ethnic service users/survivors to be involved.

*"I think we've complained about being forced to do white user involvement on the agenda of professionals. Well why should we now, as white survivors and service users, expect black people to come in on our agenda, when they haven't been part of deciding what should be on it?"*

Overall, participants felt that it was difficult to continue to engage with user involvement initiatives when they had no part to play in setting the agenda for change within services.

### **Lack of power and role in decision-making**

The fact that service users/survivors have no real power or role in decision-making within user involvement initiatives has been pointed out by several writers (Trivedi 2008; Blakey 2005; Carr 2004; Bertram, 2002). Service users/survivors are already at a disadvantage as recipients of services that do not always take their views into account. The power that the professional holds over the service user/survivor is replicated in user initiative settings. Some participants felt that there is a misconception among professionals that just by allowing service users and survivors to sit on committees they are addressing power. But unless people have the freedom to question the way services are delivered and have a real role to play in making the final decisions, the hierarchies will remain unchallenged.

*"You do the organogram, you've got your committee here, you've got your committee there, you look at where the decisions are made, that's over there somewhere. We're not actually getting close to involvement in decision-making processes, we're setting up mechanisms that look like they're involvement."*

Many of the user involvement initiatives, in the experience of the participants of this study, were not set up with a conscious political will to change hierarchies and structures. The tokenistic way in which people from minority communities were involved in these processes was proof of this. Many people had experiences of being involved in initiatives, within both statutory and voluntary sectors, where they were the sole representative for



black and minority ethnic communities and the process felt like ticking boxes in order to fulfil policy requirements.

*“You’ll get somebody come along once and once only, but it’s like, oh we’ve had a black and minority ethnic member and that person goes on to the statistics for funders, so it doesn’t matter if they’ve only been there once.”*

Tew (2005) suggests that some service users may be trying to regain some power by making a decision not to be involved, thus depriving services of their expertise. This was borne out by some of the discussions in the consultation. Participating in involvement initiatives with no real power was often experienced as furthering the disempowerment that service users/survivors from black and minority ethnic communities already faced on account of their racial identity, mental distress and position in society. Some participants had made a conscious decision not to be involved in these initiatives unless there was a clear indication that the organisation was committed to changing the hierarchies and that they had influence over decision-making. The question to ask was:

*“Are we part of the designing, because that’s what we’re talking about really, isn’t it, that’s the crux of the matter, are we designing a service together or are we panel beating an already existing system?”*

It was clear that involvement in terms of ‘hearing our views’ had lost its appeal. The need now, for many people, was for an equal role in decision-making. So it is important to clarify the purpose of involvement, how much influence a person has in the process, and how much capacity and will there is within the organisation to bring about change as a result of the involvement.

## **Support, information and payment issues**

Participants identified several procedural and structural barriers in the way involvement initiatives are set up. Many involvement initiatives are set up in the form of committees which have their own hierarchies. Traditionally, involvement in user activism has been on a voluntary basis, reflecting the personal politics and commitments of each individual service user/survivor. This philosophy of volunteerism, when transplanted into service-led initiatives, has worked as a barrier to a lot of service users from disadvantaged backgrounds.

*“Most of it is volunteer based and therefore tends to involve people who have the time and resources. The effect is that they favour particular groups, they favour the wealthy, the time rich and the resource rich – predominantly the white middle-class.”*

Getting paid appropriately for the work they do has been difficult for many service users/survivors. The issue of inappropriate, or sometimes non-existent, payment has also created a sense of being devalued. “Service users are expected to go there free of charge and then you’ve got professionals there that have been paid for. A service user’s time is just as valuable as anybody else’s time. The thing that really bugs me is that kind of, ‘we understand what you say, but actually your view is of no monetary value to us,’ attitude. People just might pay your fares, but people want a bit more than that sometimes.”

One person discussed an experience of setting up and running a user group within a statutory sector service. After over a year’s work, the payment that was promised never materialised and in the end a paid nonservice user worker took over the group.

*“Didn’t get paid, didn’t get any thank you or anything for the group, and when the paid worker came along and took over it sort of seemed like it was her that had set it up in the first place, so it was totally like one slap after another. And this is what I’m hearing at a wider level, it’s not just me.”*

The issue of getting paid for the work they put in was discussed in the context of the benefit system as well. The feeling was that, while government policies encouraged user involvement work and getting service users back to employment, the philosophy behind this did not take into consideration the anxieties and practical difficulties that a lot of service users/survivors faced. Service users/survivors have, in other contexts, talked about being paid for involvement as an explicit demonstration of valuing people’s contributions and creating a level playing field between those who are employed by and those who use health and social care services (Commission for Social Care Inspectorate, 2007). Organisations initiating service user involvement activities need to be sufficiently invested in finding out ways in which service users/survivors can be rewarded for their work without it affecting their benefits. There are guidelines in place describing how to

effectively involve service users and survivors (for example, CSIP/NIMHE guidance, “Valuing Involvement”). User involvement initiatives need to be rigorously evaluated to see how much of these guidelines are translated into practice.

While getting paid for their expertise, time and effort was important for many people, the issue was not only about money. Being provided with appropriate and clear information and support were also seen as signs of valuing people and their work. One person narrated how, after being invited to speak at the launch of the national survivor network, they were not extended the support that was needed as a disabled person to travel to the venue. Some others felt that, while they may have the expertise to contribute, sometimes support is needed in translating that expertise into effective action. The way in which most service user initiatives are set up, on a preconceived agenda with priorities already in place, the practical and on the ground support that service users need are often overlooked.

## Summary: Barriers to involvement

- Experience of coercive and punitive care within psychiatric services. Discriminatory experiences discourage people from participating in user involvement initiatives, unless there is willingness and space to explore these difficult and emotional journeys.
- Many people from black and minority ethnic communities find it difficult to have even their basic needs met, which may hamper their ability to be involved.
- Experience of racism within user involvement initiatives and user groups. The pressure to separate identities of race and ethnicity from that of a service user/survivor is felt as threatening and thwarting.
- Race and class combine to create exclusionary practices within user groups and involvement initiatives.
- The stigma within communities and racial stereotypes of mental distress make people want to disassociate with mental health initiatives.
- User initiatives are experienced as hierarchical spaces where power relations between professionals and service users/survivors are not questioned.
- Lack of role in setting the agenda and decision making. Often involvement of black and minority ethnic service users/survivors seem to be tokenistic, tick box exercises.
- Lack of adequate payment, support and information, all of which are experienced as devaluing people’s work and expertise.
- Above all, the lack of evidence that people’s life situations and experiences within services are not changing despite years of user involvement.

# Being involved: what has it achieved?

Given all the barriers discussed in the previous chapter, what has being involved in mental health initiatives meant for service users from black and minority ethnic backgrounds? Service users from black and minority ethnic communities felt that the biggest achievements were made when working within user groups set up separately from mainstream initiatives. An example of this achievement that was invoked several times was the experience of SIMBA (Share in Maudsley Black Action). While SIMBA was interested in changing services within the South London and Maudsley NHS Trust, they were also quite clear that they did not want to do it through traditional ways of committees, meetings and paperwork. Instead, they wanted to find creative ways of getting their message across, “in particular, ways that kept user/survivor interests at the forefront and didn’t leave us angry and frustrated and emotionally and physically drained” (Trivedi and

SIMBA 2002, 30). By retaining control over their involvement, service users could raise issues that were important to them and come back with pride and dignity.

The most productive and satisfying involvement for service users has been through peer groups where supporting each other and finding a common purpose were the main aims. In that sense, user involvement was of therapeutic value for the person and not primarily aimed at bringing about systemic changes within mental health services.

*“I’m speaking as somebody who has personally benefited very much from service user involvement but I don’t think it has made the slightest bit of difference in terms of any service. May be one or two practitioners have thought a bit differently. But then user involvement becomes more a therapeutic intervention than them being about what we can change.”*

## The SIMBA Story

SIMBA (Share in Maudsley Black Action) was set up by three black service users at the Maudsley hospital. The aim was to be a force of change within the South London and Maudsley Trust. The members were clear from the beginning that they did not want to spend their time doing user involvement work on other people’s terms. Instead, the focus was on using their creativity and talents in art, music, poetry and writing to raise issues and campaign for change.

SIMBA has this to say about why they decided to use creative work:

*“We reckoned that user involvement was about hearing the voices of users/survivors, and we felt we could be heard much more powerfully and effectively as real live people through our creative work than through standard user involvement systems.”*

Once established, SIMBA started getting invites to sit on committees and go to meetings. Their strategy was to send a standard letter back, saying that they would be happy to come to the meetings if the chair could give them written reassurances that their input really would make a

difference to black service users. SIMBA says that, of the 11 letters they received, only one wrote back with assurances. This strategy has helped them in reducing the pressure to be involved and choosing who they want to work with.

Using performance art and poetry, SIMBA found, had a powerful effect on the people listening. The production of creative work meant that the service users had something tangible in their hands, even if the trust did not take on their messages. Also, the feeling that each member was part of a much bigger whole had a tremendous impact on self-esteem and morale.

SIMBA does not claim that their way of doing user involvement necessarily results in lasting changes. But it worked for them – they talked about their issues, conveyed their messages, and came back with pride and dignity. It also placed the onus of change firmly with the trust, thus making it easy to see whether user involvement was just a tick-box exercise or whether they really wanted to change service delivery and work with service users/survivors. Based on “Let the Tiger Roar” (Trivedi and SIMBA 2002)

Gaining confidence and learning new skills were identifiable positive achievements of being involved in user groups.

*“The positive side of it is that people get a lot of useful experience, they gain a lot of confidence, learn some skills. It can be life enhancing, usually, not always. Even through struggle people learn a lot and they meet other service users and they get a stronger understanding of how the system works.”*

But others were more sceptical of the confidence building and skills development aspects of service-led user involvement initiatives, especially when it is not accompanied by a willingness to change services and practices. User involvement then becomes an exercise in itself.

*“It’s a bit of a trade off really – we’ll provide you with confidence building skills and you provide us with stuff that we can say we’re doing user involvement and we’ll be both happy and we won’t cause too many waves.”*

The overwhelming feeling that conventional, service-led involvement is not working is based on the fact that there has been no perceivable change in the way people were treated within services. People felt used, devalued and disempowered. For people from many black communities, this resonated with the way in which their communities and countries had been exploited historically.

*“Most of these systems are so embedded in the philosophy of slavery, in the sense that you have a few who dominate the others and keep pulling and pulling and pulling without actually putting anything back in. And I think people within black communities are becoming mature to the realities ... and that’s why there probably is a lack of user involvement because they’re not interested, as simple as that. So they’re actually voting with their feet.”*

There was a huge discrepancy between the way people were treated as user consultants and when they were accessing services. If user involvement was about listening to service users, why was it difficult to listen to them when they were most involved – inside wards accessing treatment? An experience that one of the participants described was a poignant example of this.

*“Last year I ended up in hospital. On the Monday and Tuesday I was training. Everybody was very attentive and respectful*

*and wanted to hear what I had to say. On the Wednesday I got sectioned and by evening I was in the ward where nobody had the slightest interest in what I was saying or what my views were and it was all down to my pathology. And I was suddenly a total non-entity and it was really weird how suddenly you could overnight just change...be treated so differently. People are treated with respect, in terms of user involvement work, but then when they end up in that situation they just become a number.”*

While this disempowerment is a reality for service users/survivors across the board, it is felt more acutely by people from black and minority ethnic communities, given the way mental health services have treated them historically. It also reinforces the scepticism that a lot of people have about the meaning and usefulness of user involvement.

*“The stark reality is that for a lot of people, particularly young people from minority groups, their experience of involvement is around the harsh end of services. So they are thinking, what’s that got to do with me? How is [user involvement] going to change the way I’m going to be sectioned and carted off from my house to the ward? They don’t see the connection between me being involved in influencing policy on the one side when I’m out and how that’s going to impact on the way I’m treated when I’m in hospital or even in the community for that matter.”*

Research shows that several minority ethnic communities continue to be over represented in mental health services, and have higher rates of detention under the Mental Health Act and of seclusion compared to the white population (Count me in census; Ali et al 2007). With at least three decades<sup>12</sup> of user involvement behind us, why is there no significant change in the way people experience mental health service delivery? This was the key question that people voiced when thinking about the achievements of user involvement.

On the whole, despite user involvement now being firmly in place in policies, service users/survivors from black and minority ethnic backgrounds were not convinced of its value

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12. The formation of the Mental Patients Union and the protest action in the context of the closure of Paddington day clinic in the early 1970s could be seen as the beginning of “user involvement.” See <http://www.mdx.ac.uk/WWW/STUDY/MPU.htm#top> for more details of this history [accessed June 2008].



in changing their life situations or the way in which they were treated within mental health services. There needs to be a complete re- definition of the way involvement is 'done,' if it is to be meaningful. People were more interested in and committed to working within their communities than being involved in larger mainstream involvement initiatives. This was acknowledged by service users/survivors from all backgrounds who took part in this consultation.

## **Summary: User involvement**

### **What it has achieved**

The biggest achievements were made when working within user groups set up separately from mainstream initiatives. This helped focus on race issues and in defining the parameters of involvement.

- Involvement of service users/ survivors from black and minority ethnic communities may have changed the attitudes of individual practitioners.
- Involvement in user groups has helped in accessing support from other service users/survivors and finding a common purpose.
- Participation in user involvement initiatives has had a therapeutic value to some.
- Gaining confidence and learning new skills.

### **What it has not achieved**

- There have been no perceivable changes in the way the mental health system treated people from black and minority ethnic communities. People from some communities are still over-represented in terms of admission into in-patient care, sectioning under the Mental Health Act, over medication, diagnosis of schizophrenia and so on.
- Empowerment. There is a huge discrepancy between the way people are treated when they are user consultants and when they are accessing services.
- Changing people's lives.



# Effective involvement: recommendations for change

*“Sometimes you just have to walk away and say you’re not interested.”*

Given the dissatisfaction with the current scene of user involvement, what needs to be done if service users/survivors from black and minority ethnic communities are to have a better deal? The feeling was that being involved in short-term initiatives and projects, whether within larger mainstream organisations or within the statutory sector, was not achieving the desired changes. These initiatives were not sustainable as we had no control over shifting agendas and funding priorities. One participant put it succinctly:

*“The solution to me has to come from a sense of where communities and human potential is the priority rather than setting up organisations...it is about human potential and human potential means everybody is different.”*

NSUN’s overture to work proactively with service users/survivors from black and minority ethnic communities was welcomed, but not without stipulations. Partnership with Catch-a-Fiya, and through it, with community groups would have to be based on a commitment to recognise the diversity of work that service users/survivors are doing within their own communities and localities, sustain people’s potential, enable independence and build capacity to be self-reliant. The following are some of the key areas of work and strategies for development suggested by participants.

## Link mental health with broader black and minority ethnic rights based initiatives: a broader social change agenda

Mental health is only one aspect of a person’s life. Much of the racism and discrimination that people from black and minority ethnic communities face within services is a reflection of the structural inequalities within society. In that sense, working to change mental health services has to be linked with changing the overall situation of black and other minority ethnic groups in this country. Political action, linking work in mental health with work in education, forensic services, citizenship rights, social inclusion etc., is the way to change.

*“I would take mental health out of health totally and put it into the rights based, social context based framework... I think a lot of issues are about money, employment, housing...I don’t know why health has kind of appropriated distress...If we address some of those social issues, some of those rights issues, people do recover or people do find a way.”*

Some participants felt that this was something that Catch-a-Fiya, as a national body representing black and minority ethnic service users/survivors, could enable.

*“I’d like to see Catch-a-Fiya make more links with black political organisations and make those really explicit so that people can’t marginalise us, and know that we’ve got a body behind us which is political as well...”*

## Invest in building relationships

While some participants felt that as service users/survivors we needed to work towards ‘a common purpose,’ there was no illusion that this common purpose would be achievable unless considerable effort went into building meaningful relationships between generic mental health initiatives and black and minority ethnic communities.

This was clearly evident when NSUN was called to explain the objectives and agenda behind commissioning the current piece of work. There was a strong feeling among all participants that national organisations were often perceived as middle-class institutions. It was felt that a lot of work needed to be done before the person on the wards would identify themselves with these organisations.

Relationships also needed to be built between different minority ethnic communities. The increasing tensions related to broader socio-political issues like immigration, the so-called ‘war on terror,’ poverty and economy have created rifts between communities. Within health and social care, the ways in which the government and the statutory sector fund user involvement have further increased distance between different black and minority ethnic communities in areas where they have had to compete for funding. There have been instances (for example in Bradford and London)

where funding for services targeting a specific ethnic minority community had been cut while new funding was given for services targeting another ethnic minority community. This was experienced as a 'divide and rule' policy, creating resentment amongst communities. It was felt that national networks had a role to play in rebuilding these relationships.

Political alliances also needed to be made with black professionals. Often, in research so far, black professionals are seen as a hindrance to the involvement of service users/survivors from black and minority ethnic backgrounds. This is because often the opinions of professionals are substituted for the voices of service users/survivors, purely because they are from the same ethnic or racial backgrounds (Begum 2006). Some participants felt that it was important to remember that black professionals may also hold prejudiced views about service users/survivors. But, overall, the feeling was that it was important to work with professionals and politicise them in order to change the Eurocentric system in which they worked. The stigma of mental distress can be reduced only if we work together as galvanised, politicised communities.

*"If we don't work together as a community then how are they going to learn how to best serve their communities within the hospitals? How are they going to know that the model they are using is not sufficient for the people who they are dealing with?"*

## Support agendas set by communities at the local level

*"[Increasing black and minority ethnic user involvement] is about priorities, it's about what matters to people in a locality. If you're Asian and you live in East London, what matters, what do you need to see change, what is the important issue and that's what we should be looking at, more so than numbers of people, I think."*

It seemed very clear that the time had passed for expecting black and minority ethnic service users to work on initiatives with agendas and priorities set elsewhere. Service users from black and minority ethnic backgrounds have continued to do work on the ground, despite being seen as underrepresented in user initiatives. This is because the kind of work done locally has not had the recognition or support that large national initiatives have had.

If things were to change, local initiatives need to be identified and supported. The focus should be on pulling together and coordinating some of those activities. National networks like NSUN and Catch-a- Fiya can play a role in this. A clear suggestion that came up in this context was to start going into localities, looking at what is happening there, and start having clear conversations about what support was needed and how it can be generated.

There were several examples of influential black and minority ethnic projects that did significant work for a short period and then had to fold because of resource and capacity related issues. Long term solutions need to be found if this situation is to be changed.

## Decentralise resources and enable autonomy

National organisations need to be mindful of the delicate balance between being supportive and taking over. If this is to happen there needs to be a certain decentralisation in how resources are allocated and controlled. Resources have to be transferred to where it is needed most and the local groups need to have independence in order to be sustainable.

*"...people like yourself [national networks, people with access to resources] can help them to formulate and organise themselves, but that has to happen from a power base, and that power base needs a transfer of a certain amount of resources to boost up marketing, advertising, proper administrative support, and then these consultations to me would be more practical if you're on the ground, action learning, people trying out things, learning to come alongside executives, learn the skills and get on with doing their own stuff."*

The example of Strategies of Living (a programme by the Mental Health Foundation) was invoked as a possible model. This model found resources for people with ideas and the ability to execute those ideas in doing work that they found important.

Some participants had experiences of setting up and running black projects within larger mainstream organisations. In some cases, this experience has been frustrating because of the changing agendas of the organisation, in which the black project had no say. Often projects came to an end because of lack of continuing support.

*“We may find that we don’t have ultimate control over those opportunities. If we rely on the Trust, the local authority, the big national charity, we’re always going to run the risk that those big organisations are going to say, sorry, this year we’re not doing involvement.”*

The only way around this was to create usercontrolled services. It was pointed out that the ultimate aim should be to ensure that local groups had the capacity, resources and the autonomy to sustain their work without being controlled by a larger, influential organisation.

## **Invest in people’s potential**

As suggested earlier, what constitutes involvement need to be re-examined. If involvement is seen as getting people to sit around a table and give their opinions on a certain service or initiative, it will be difficult to sustain people’s interest, especially if there is not enough evidence to show that their opinions and suggestions have been translated into action and change.

It was suggested that people who want to be involved need to be clear about their interests and what they would like to work on. Practically, this means identifying the varied potential that each person or group has and investing in that potential.

*“Many people don’t know where the capital is in the community. But there is capital and there are power bases and there is influence. And unless you’re able to identify that and then from there whatever you’re birthing, birth it within those power bases, within those communities, within those influences, you’ll always be reliant on funding, you’ll always be reliant on something else.”*

Investing in people turns the focus away from a person’s mental health status to a person’s role in the community. This, it was felt, was a more holistic way of working to enable change on the ground, the benefit of which will be felt across the society.

## **Mobilise solidarity and support through peer groups**

The focus on user involvement as giving service providers what they want reduces the focus on one of the important functions that user groups fulfilled – that of peer support and mutual help groups.

*“It is really important that service users have support groups, not just involvement groups. People didn’t just meet together in order to give service providers what they wanted. It’s every bit as important as involvement, making sure that we actually support each other, because very often services don’t support us in the way in which we want to be supported.”*

The importance of finding opportunities to share experience and network with other service users/survivors has been studied earlier, where specific attention was given to black and minority ethnic service users and their needs (Branfield et al 2006). Lack of resources often limited the opportunities that service users/survivors could access. Big national charities and organisations could do more to actively encourage and support service users/survivors from black and minority ethnic communities to attend conferences and networking events. National organisations like NSUN and Catch-a-Fiya can and need to do more to provide resources and support in this area.

*“...giving black and minority ethnic groups and individuals an opportunity to come together and share information, that always helps a lot because it’s quite hard for people to find the time and the funding to do that. It depends on doing really good networking – that’s one thing [NSUN/Catch-a-Fiya] should be able to do.”*

There was a strong feeling that the people who have managed to break out of the oppressive relationship with the mental health system had a responsibility to provide support to those who are still vulnerable. Mentoring people to identify and develop their interest areas was suggested as a possible solution forward. Support can also be developed around helping people who want to work in user involvement ask pertinent questions around the scope of involvement, power to set agendas and make decisions etc. in order to reduce disillusionment.

## **Set minimum standards for involvement**

As discussed, earlier, many people felt that service users/survivors from black and minority ethnic communities were pulled into involvement initiatives in a tokenistic manner. Often, there were no clear aims or outcome measures to these initiatives. It was felt that we need to set minimum standards, specifying what we expect from organisations that want our involvement, including support,

opportunities of personal development, financial benefits, role in decision making etc. The question then was how we would ensure that the minimum standards were enforced. One participant narrated an incident where the service users in a borough refused to participate in user involvement activities until the authorities decided to meet their terms. The point of the strike was to show a united front. It was suggested that we explore the possibility of a national body that would have the remit to ensure that the minimum standards were adhered to. The standards could be written into service level agreements.

## Evaluation (and documentation) of user involvement

It was pointed out that, while the government produced policies and guidelines around user involvement, there has never been an independent evaluation of user involvement. Where monitoring of user involvement activities does take place, the focus is on content and processes rather than outcomes (Carr 2004).

Evaluating user involvement initiatives was seen as an important issue for several reasons. First of all, user involvement needs to be evaluated in order to record service users' views on the processes of involvement and the effect of their input. Useful tools for measuring this have been developed by service users themselves (Trivedi 2003), and by NIMHE (2007).

Secondly, evaluating user involvement will help stop services and service users making the same mistakes. Good practices can be highlighted and replicated. Thirdly, it is important to see how much change actually happens as a result of involvement. As we have seen already, the biggest reason why service users/survivors are cynical about user involvement is because they don't see their viewpoints and input translated into action. Evaluating user involvement will require services to show that changes are being made or, if not, explain why actions are not taken. Ultimately, evaluating user involvement had a purpose for service users/survivors themselves.

*"People deserve to have their achievements commemorated and shared, because they can work their hearts out and be forgotten. We need our own literature. We need it as a survivor movement so that we don't have to keep reinventing the wheel, to know we've achieved a lot, we've actually created a lot of tools and a lot of interesting books that we can all benefit from."*

## Summary: Enabling effective user involvement from black and minority ethnic communities

- Link work to change mental health services with broader race and rights based initiatives like education, forensic services, citizenship rights, social inclusion, employment, income generation etc.
- Build relationships between mainstream groups and black and minority ethnic groups, between communities and between professionals and service users/survivors.
- Enable professionals from black and minority ethnic communities to think about race related issues in their practice.
- Actively seek out groups and organisations working locally, highlight their work and endeavour to support and sustain them.
- Support local organisations to develop autonomy and access sustainable resources.
- Invest in people's potential. Acknowledge that mental health is only one aspect of a person's life.
- Mobilise solidarity and support through peer groups, sharing learning and enabling networking between groups.
- Offer mentoring and support to people who might be newly interested in user involvement. Help them identify their interest areas and ask questions to clarify the scope of involvement and their role in it so that they can make informed choices about participating.
- Develop national, regional or local standards for involvement. Mobilise a united front to uphold these standards.
- Evaluate user involvement initiatives, focusing on outcomes rather than content and processes.
- Document work in user involvement so that we can learn from our experiences, celebrate achievements and create our own history.



# Looking to the future

The final stage of this consultation process was set up to specifically discuss the ways forward for the two national networks (NSUN and Catch-a-Fiya). The overall failure of the mainstream service user/survivor movement to represent issues of black and minority ethnic service users was once again acknowledged. For this reason, many of the people we would be working with might be sceptical of yet another effort to work in partnership. However, the group also acknowledged that it was important not to lose the enthusiasm, faith and potential that still existed among service users to work collaboratively in order to change mental health services. The focus, then, was on how to do things differently.

In the course of the discussion, several project ideas were identified by participants. These included the creation of a life story archive, envisaged as a multi-purpose narrative resource, with the specific aim of recording the histories of people and communities, a “Count Me Out” census, which would focus on helping people see past bad experiences and move on with life, a project that will map the work done by small local groups and highlight achievement, a systematic evaluation of user involvement initiatives to examine what these have achieved etc.

However, the consensus was that we need to establish a clear structure and ways of working together before launching into projects in order to prevent burn out and loss of faith. The following strategic recommendations were made:

## A. Set up a steering group

- Establish a steering group with membership from both Catch-a-Fiya and NSUN, with the specific aim of strengthening partnership working. This will promote co-ownership of the partnership.
- The Steering Group will have the remit to produce a business plan and structures to take this partnership work forward.
- One of the main tasks of the steering group should be to define a clear structure that will support people to work effectively, sustain their energy and prevent burn out. Adopt a sound business relationship with clear visions and work plans.

- NSUN to pursue funding to enable the group to meet at appropriate intervals to set this work in motion.

## B. Shift the locus of leadership

- Service users involved in this study will provide the direction for this work at the outset, with service users from black and minority ethnic communities taking on the leadership. This was in agreement with the discussions on the importance of setting our own agendas.

- NSUN and Catch-a-Fiya will support this work and establish partnerships with other groups and service users.

## C. Improve communities

- The focus of the work should be to improve communities. There should be a commitment to acknowledge the diversity of work that service users are doing within their own communities and localities.

- Establish relationships with local projects/ groups, going into localities, looking at what is happening there and starting conversations about capacity and sustainability needs.

- Strengthen relationships between communities and between professionals and service users.

- Create alliances with work happening in other areas like education, housing, income generation, social inclusion, human rights etc. The aim is to place mental health work within other social development initiatives.

## D. Build capacity of smaller groups

- Focus on sharing learning and identifying resources to strengthen smaller black and minority ethnic groups and their work. (One of the main aims of both NSUN and Catch-a-Fiya is to help build the capacity of local groups).

- Work with an aim to decentralise resources, taking on a supporting role rather than a management role.

- Build the capacity of interested individual service users through mentoring and peer support.



## **E. Document and communicate**

- Establish an organised political voice, for commenting and campaigning on racism and mental health.
- Facilitate networking, information sharing and communication between groups and individuals. Establish a structure for communicating local and national news and information to a broad range of service user organisations.
- Document the work of black and minority ethnic organisations and groups. It is important to celebrate our achievements, signpost good practice, and highlight areas that need further development.

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# Appendix 1

## TOOTS guidelines for partnership working

Partnership working with service user/survivor led black and minority ethnic organisations is facilitated by the following:

### Values

- A genuine commitment from all partners to supporting race equality and changing organisational practices that may be discriminatory to service users/survivors from black and minority ethnic communities
- Mutual respect between partners and avoidance of competition
- Open mindedness towards ways of doing things that may stem from different and diverse backgrounds and experiences of people and communities. The fact that it is different does not mean it is bad or wrong, or will not work
- Honesty and openness. Each partner needs to feel comfortable about being honest and open and this honesty and openness should be respected by both sides
- Equality and fairness. Partners may come from unequal power structures. Therefore each partner needs to be aware of the power dynamics between them and work towards equality. Patronising and tokenism should be avoided and there should be a true sense of fairness.
- Sensitivity in language and actions. Each partner may have different ways of expressing and doing things. Respecting these will help determine the success of the partnership.

### Setting up the partnership

- Establish a shared vision: each partner needs to agree on a shared vision for the partnership. The shared vision should be ironed out in detail so as to avoid confusion later.
- Ensure equality in the partnership: acknowledge the specific knowledge and expertise both of the black and minority ethnic and of the generic organisations.
- Be democratic in leadership and decision making: ensure each partner is fully involved. This does not only mean shared tasks or consultation. Let each organisation take the

lead in aspects of work for which they have particular skills.

- Agree clear roles: the roles of each partner should be well defined so as to avoid confusion. Each partner should then take full responsibility for their particular role
- Have realistic and clear expectations: each partner should be agreed on the goals for the partnership and what is to be realistically expected of each partner
- Identify development needs: ensure each partner has the necessary skills and capacity for the joint initiative. If gaps are identified, provide necessary training and development opportunities

### On-going management of the partnership

- Share responsibilities: many tasks within a partnership can be carried out jointly. Know what each partner is capable of and use this to the advantage of the initiative and to furthering the partnership.
- Ensure accountability: there should be clear lines of accountability for the work. Each partner should be able to identify the individual responsible for any aspect of the work.
- Have continual information sharing: each partner needs to be kept up-to-date about what is happening with the other in order to plan and have things running smoothly. Use appropriate languages and methods of communication to share the information
- Share learning and good practice: promote opportunities to learn from each partner's work, highlight good practice extensively and use it to aid partnership working.
- Acknowledge successes: celebrate the successes along the way. This does not have to wait till the end of an initiative. All partners need to be acknowledged for their achievements and for successes in the initiative as a whole.
- Identify difficulties: try to address these as they arise. Do not sit on a difficulty and hope that it will disappear; bring it out into the open and get it cleared up.
- Review the initiative regularly: there should be consistent opportunities to review the

# Appendix 2

partnership and its work to make sure that things are going according to plan, are on target and on schedule. These occasions will also provide opportunities to iron out any difficulties or grievances.

- Provide on-going support for addressing race equality: partners may need help with changing attitudes and practices or with dealing with personal experiences of discrimination. Be creative about the forms of support which are offered.
- Provide independent support for managers of organisations in the partnership. Staff can come to managers to talk through issues for them; managers also need someone whom they can approach.

## Good Practice

- Agree quality assurance standards for the partnership: these should be based on standards that respect and take into account each partner's definitions of quality and methods of measuring quality.
- Be creative: there is usually more than one way to work in partnership. Explore imaginative ways of addressing the needs and concerns of users/survivors from black and minority ethnic communities even though these may seem different from generic organisational practices.
- Be flexible: be prepared for change and difference. If usual ways of doing things are not working for users/survivors from black and minority ethnic communities, try something new. Real partnerships are built on the courage and willingness to change.

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- Frank Palma
- Jan Wallcraft
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The group was facilitated by Patricia Chambers, Catch-a-Fiya manager (2009 – 2010), with support from Sarah Yiannoullou, Managing Director of NSUN.





together we  
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