# Dancing to our own tunes:

## Reassessing black and minority ethnic mental health service user involvement

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# Acknowledgements

# Executive Summary

## THE PURPOSE AND SCOPE OF THIS CONSULTATION

Engaging people who use services in developing those services, a process generally known as "service user involvement," is now an intrinsic part of policy. User involvement includes participation in policy driven, organisational initiatives, and in peer groups for personal support and/or political campaign. It is based on the idea that service users/survivors are experts in their own experiences and that self-organisation and self-determination are crucial in their journey to recovery.

> *"[Increasing black and minority ethnic user involvement] is about priorities, it's about what matters to people in a locality... what do we 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."*

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. Evidence shows an "under-representation" of service users/survivors from black and minority ethnic backgrounds in user involvement activities, even as their over-representation in services continues. In reality, mainstream involvement initiatives often excluded black and minority ethnic service users with the label of being "hard to reach." Experiences of being involved in tokenistic gestures to increase "black bodies" on committees have often been negative.

We wanted to explore these experiences further by finding out from black and minority ethnic service users their experiences of being involved, both the problems and the possibilities. We wanted to find out from service users from white British backgrounds their experiences of involving black and minority ethnic service users in mainstream initiatives, user groups etc. And, together, we wanted to explore how to work more effectively in collaboration to increase the influence of service users from black and minority ethnic backgrounds. The objective was not to access representational data through a large research process, but to concentrate on the lived experience of people who had participated in various user involvement initiatives and learn from that.

## THE PROCESS OF CONSULTATION

The participants were recruited through the NSUN and Catch-a-Fiya networks, and brought together a range of experiences of participating in user involvement initiatives. The consultation took the shape of a day-long meeting with service users and survivors from black and minority ethnic communities, a half-day meeting with service users and survivors from white British backgrounds, and three one-to-one interviews. The findings from these consultations were presented in a day-long workshop to which everyone who participated in the initial consultations were invited. The recommendations were developed in this workshop.

# KEY LEARNINGS FROM THE CONSULTATION

Consultation is not involvement. If black and minority ethnic service users/survivors are to be involved meaningfully in mainstream initiatives, there has to be structural changes in hierarchies, assumptions, ways of working, power within institutions, resource allocation, the location of decision making, and the way people are treated within mental health services and outside them.

> *"I think we've complained about being forced to do 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?"*

## Barriers to involvement

Discriminatory experiences, including racism and coercive and punitive care, 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 threatening and thwarting.

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, there is very little evidence that people's life situations and experiences within services are changing despite years of user involvement.

> *"... people get a lot of useful experience, gain a lot of confidence, learn some skills. It can be life enhancing... Even through struggle people learn a lot and they meet other service users and they get a stronger understanding of how the system works."*

## 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.

## User involvement - What it has not achieved

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.

> *"If user involvement is about listening to service users, why is it difficult to listen to them when they are most involved – inside wards accessing treatment!"*

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.

> *"I would take mental health out of health totally and put it into a 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."*

## RECOMMENDATIONS FOR EFFECTIVE USER INVOLVEMENT

### A broader social change agenda

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.

### Invest in building relationships

Rebuild relationships between communities and between professionals and service users/survivors.

### Work with professionals

Enable professionals from black and minority ethnic communities to think about race related issues in their practice.

## Support agendas set by communities set at the local level

Actively seek out groups and organisations working locally, support local organisations to develop autonomy and access sustainable resources. The time had passed for expecting black and minority ethnic service users to work on initiatives with agendas and priorities set elsewhere.

## Invest in people's potential

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

## Develop networking

Mobilise solidarity and support through peer groups, sharing learning and enabling networking between groups.

## Mentor new service users

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.

## Develop involvement standards

Develop national, regional or local standards for involvement. Mobilise a united front to uphold these standards.

> Participants acknowledged that the mainstream service user/survivor movement had not fully represented issues of black and minority ethnic service users. For this reason, many people 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 from all backgrounds to work collaboratively in order to change mental health services.

## Monitoring and evaluation

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.

## RECOMMENDATIONS FOR NSUN'S FUTURE WORK WITH BME COMMUNITIES

Establish a steering group (SG)

With membership from both NSUN and Catch-a-Fiya. The specific aim would be to strengthen partnership working and promoting co-ownership. The SG will be tasked with defining clear structures and a business plan. NSUN to pursue funding to enable the work of the SG.

## Shift the locus of leadership

In agreement with the discussions of setting agendas, black and minority ethnic service users/survivors will provide the leadership for this work.

The two networks to provide support and establish partnerships with other groups and individuals.

## Improve communities

Acknowledge the diversity of work being done within communities and localities and provide support for this work.

Create alliances with broader social change movements and work and place mental health work within other social development initiatives.

### Build capacity of smaller groups

Take on a supportive role rather than a management role, with an aim to decentralise resources.

Build capacity of interested individuals through mentoring and peer support

### Document and communicate

Establish an organised political voice, for commenting and campaigning against racism. Facilitate networking, information sharing through a proper structure of communication.

Document the work of marginalised groups, signposting good practice, sharing information and highlighting areas for further development.

# 1.   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 (DoH 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 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.

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**1.** 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.

**2.** The term "black" is used in this document to refer to people of African, Asian and Caribbean origin. It acknowledges the political use of the term to refer to people who have been historically discriminated against on the basis of their skin colour. However, this usage does not deny the vast diversity and difference within and between these communities.

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 had 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. Chapter 6, 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 Chapter 7 are specifically aimed at increasing partnership working between NSUN and Catch-a-Fiya, but are of relevance to those wanting to work specifically 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.

**3.** NSUN, "Inaugural mission, aims and values," http://www.nsun.org.uk/jcms/images/mission_and_aims.pdf. May 2007.

**4.** Catch-a-Fiya, "What we are doing,"
http://catchafiya.org/index.php?option=com_content&task=view&id=13&Itemid=27, November 2006

# 2.  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 fifteen 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 movement 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 made some 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 under-representation. 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 sited above.

## THE ANALYSIS

The group meetings and interviews were recorded and transcribed. The transcripts were analysed by the lead writer 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.

# 3.   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 terms of rates of admission into in-patient care, of sectioning under the Mental Health Act, of coercive treatment, of diagnoses of schizophrenia and so on (Healthcare Commission 2007). The fact of their over-representation 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 (DoH 1998) and in giving people "more say" or "a stronger voice" (DoH 2006a, DoH 2006b). But 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 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.

# 4.  Barriers to Involvement

## NEGATIVE EXPERIENCES WITHIN MENTAL HEALTH SERVICES

The overall experiences of dealing with mental health services have 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 over-represented 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 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's 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 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 for. 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 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 tend to involve people who have the time and resource. 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 nonexistent, 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 non-service 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.*

# 5.   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 SIMBA Story

*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.*

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*The stigma within communities and racial stereotypes of mental distress make people want to disassociate with mental health initiatives.*

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*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.*

The most productive and satisfying involvement for service users have 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."*

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 (Healthcare Commission 2007; Ali et al 2007). With at least three decades 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 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 has 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.

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**5.** 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].

## 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.*

# 6. Effective Involvement: What Needs to 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."*

The only way around this was to create user-controlled 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.*

# 7. 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.

# References

Ali, S, S.P. Dearman and C McWilliam (2007). "Are Asians at Greater Risk of Compulsory Psychiatric Admission than Caucasians in the Acute General Adult Setting?" Medicine, Science and the Law, 47.4, 311-14.

Begum, Nasa (2006). Doing it for Themselves: Participation and Black and Minority Ethnic Service Users. London: SCIE/REU.

Bertram, Mark (2002). "User Involvement and Mental Health: Critical Reflections on Critical Issues." www.psychminded.co.uk. Accessed on 28 April 2008.

Blakey, Heather (2005). Participation – Why Bother? The Views of Black and Minority Ethnic Mental Health Service Users on Participation in the NHS in Bradford. Bradford: International Centre for Participation Studies.

Blakey, Heather (2006). "Participation – Why Bother?" Mental Health Today, May, 23-26.

Branfield, Fran et al (2006). Making User Involvement Work: Supporting Service User Networking and Knowledge. London: Shaping Our Lives.

Carr, Sarah (2004). Has Service User Participation Made a Difference to Social Care Services? London: Social Care Institute for Excellence.

Commission for Social Care Inspection (2007). Benefit Barriers to Involvement: Finding Solutions. London: CSCI.

Crawford, Mike, Deborah Rutter, and Sarah Thelwell (2003). User Involvement in Change Management: A Review of Literature. London: NCCSDO.

Department of Health (1998). Modernising Mental Health Services: Safe, Sound and Supportive. London: Department of Health.

Department of Health (1999). National Service Framework for Mental Health: Modern Standards and Service Models. London: Department of Health.

Department of Health (2005). Delivering Race Equality in Mental Health Care: An Action Plan for Reform Inside and Outside Services. London: Department of Health.

Department of Health (2006a). Our Health, Our Care, Our Say: A New Direction for Community Services. London: Department of Health.

Department of Health (2006b). A Stronger Local Voice: A Framework for Creating a Stronger Local Voice in the Development of Health and Social Care Services. London: Department of Health.

Healthcare Commission (2007). Count Me In2007: Results of the 2007 National Census of Inpatients in Mental Health and Learning Disability Services in England and Wales. London: Commission for Healthcare Audit and Inspection.

Health and Social Care Advisory Service (2005). Making a Real Difference: Strengthening Service User and Carer Involvement in NIMHE. London: NIMHE.

National Institute for Mental Health in England (2007). Valuing Involvement: Monitoring and Evaluating Service User and Carer Involvement. London, NIMHE. http://www.nimhe.csip.org.uk/silo/files/involvement-monitoring-and-evaluation-july07.pdf [Accessed 18 July 2008]

National Institute for Mental Health in England (2003). Engaging and Changing: Developing Effective Policy for the Care and Treatment of Black and Minority Ethnic Detained Patients. London: NIMHE.

Tew, Jerry (2005). "Power Relations, Social Order and Mental Health." In Social Perspectives in Mental Health. Edited by Jerry Tew. London: Jessica Kingsley.
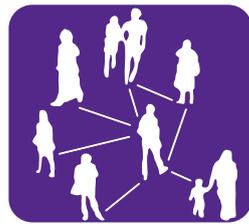
Trivedi, Premila (2001). "Never Again." Openmind, July/Aug.

Trivedi, Premila et al (2002). "Let the Tiger Roar." Mental Health Today, August, 30-33.

Trivedi, Premila (2008). "Black Service User Involvement: Rhetoric or Reality?" In Mental Health in a Multi-Ethnic Society. Edited by Suman Fernando and Frank Keating. London: Routledge.

Wallcraft, Jan, Jim Read and Angela Sweeney (2003). On Our Own Terms: Users and Survivors of Mental Health Services Working Together for Support and Change. London: The Sainsbury Centre for Mental Health.

# nsun
## national survivor
## user network