

Issue 34

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Race on the Agenda

agenda

ROTA is an independent research and social policy charity which focuses on the issues facing Black, Asian and minority ethnic (BAME) communities.

ROTA's policy work is evidence-based. Everything we do is informed by the views and real life experiences of BAME communities and the organisations set up to serve them.

Our definition of 'race' encompasses all the protected characteristics under equality legislation including:

- colour
- nationality
- ethnic or national origin

Consequently we use the term BAME to refer to all groups which are discriminated against, including (but not exclusively) people of African, Asian, Caribbean, European and Eastern European, Irish, Greek, Turkish, Jewish, Roma and South East Asian descent, as well as refugees and asylum seekers.

In this publication different authors may use different definitions or abbreviations to refer to BAME communities. We have left these as they have been given to us and have not attempted to edit them to our understanding or house style.

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Our objective is that this issue of *Agenda* is a useful resource in your own work, and we'd like to hear your feedback. Please email us at [rota@rota.org.uk](mailto:rota@rota.org.uk) with any comments you may have.



# From the editor

This issue of *Agenda* is a departure from the norm. The entire magazine has the theme of mental health and BAME communities.

by **Rahana Mohammed, Head of Policy, ROTA**

Health is one of ROTA's policy priority areas. The mental health needs of people from BAME communities are of particular concern nationally, regionally and locally for the organisations which are trying to serve them.

Many BAME communities experience poorer mental health in comparison to the general population. There are several reasons for this, including the impact of everyday and structural racism – both as a causal factor for economic and social disadvantage and distress, and individual or community factors, including cultural behaviours.

Research also shows that there is great variation in how different BAME communities access different mental health and related services, and in their experiences as service users.

We have gathered together a number of experts in the field who present their view of the mental health landscape as experienced by BAME communities. We hear from national representatives, mainstream and specialist organisations, individuals and community grassroots organisations to bring a broad brush to this critical topic.

Barbara Nea sets the context for the magazine, analysing outcomes and experiences, especially in the light of the Delivering Race Equality in Mental Health Care (DRE) programme. Then Melba Wilson considers the historical framework within which the DRE action plan was placed, and continues with a look at the current national picture.

Victor Adebawale is ROTA Patron and Chief Executive of Turning Point. He presents his organisation's involvement in the New Horizons agenda – the successor to DRE – and is feeling positive about the future of health inequalities. Oliver Hilbery starts to narrow the focus by talking about how multiple needs and exclusions will be addressed in the world of a coalition government.

A political identity as a survivor has given Jayasree Kalathil the means to research and campaign on behalf of BAME mental health users. She describes herself as having strong views on what it means to remain well, and in her article talks about user involvement initiatives and whether they are meaningful for BAME communities.

Next we look at a short review of a south London project – Canerows and Plaits – which does engage service users from BAME communities. Author and artist Dwight Reynolds reports on the positive feedback received and the genuine involvement users of the group feel in the project.

Alison Cobb from Mind reflects on their approach to BAME access to mental health services with their Diverse Minds programme. She also showcases two projects which are delivering support, advocacy and access to refugees and asylum seekers in Leeds and London.

Three case studies featuring organisations working with Armenian, Somali and Chinese communities follow. They illustrate the issues and challenges highlighted so far in the magazine and explain some of the diverse cultural needs of these groups.

Deryck Browne of NACRO's Mental Health Unit takes us through the disproportionality experienced by BAME people in mental health services and the criminal justice system. He discusses the critical interface between these two systems and looks at an often-forgotten group – foreign nationals – in UK prisons.

Finally, Patrick Vernon of the Afiya Trust argues that in the new era of cuts and coalition, race equality in mental health must still be high on the agenda. His article concludes with the hope that the Big Society will acknowledge the expertise and skills of BAME organisations in providing for their own communities.

# Black, Asian and minority ethnic people and mental health and wellbeing

Setting the scene for this issue of *Agenda*, **Barbara Nea**, Senior Policy Officer at ROTA, investigates mental health inequalities in terms of outcomes, and looks at access and experience of using mental health and related services.

## Outcomes

The most recent Count Me In census,<sup>1</sup> which monitors the ethnicity of inpatients and people subject to the Mental Health Act, found that 22 per cent are from BAME communities, even though we make up only eight per cent of the general population.

Inpatient admission rates are over three times higher than average among mixed white/black and black groups, with rates nine times higher for the 'other black' group. Similarly, rates of patients subject to the Mental Health Act (including Community Treatment Orders) are higher than average, particularly for these groups and also for other white groups.

Rates of referral from general practitioners (GPs) and community mental health teams are lower than average among black and white/black groups, whereas rates of referral from the criminal justice system are higher.

Certain BAME groups, in particular Indian, Bangladeshi, black Caribbean and other black groups, are also more likely to be subject to Community Treatment Orders (CTOs), which are used as an alternative to detaining patients in hospital. Under CTOs, patients are supervised by a doctor, nurse or social worker, with care plans which can include medication and therapeutic treatments. They can also specify where patients live or put restrictions on where they can go. If patients continue to refuse to adhere to their care plans, they will be re-detained.

Once within the mental health system, there is evidence that certain groups of BAME patients' experiences are more negative than those of white patients, with

differences in decisions about treatment, medication and restriction.<sup>2</sup>

Not only do certain groups experience higher rates of admission to and detention in hospitals, but some, in particular black Caribbean and white/black Caribbean mixed groups, stay, on average, in hospital for longer.

Seclusion rates are higher among the other white and mixed white/black Caribbean groups. Patients from the mixed white/black, black, white Irish and other white groups have a higher than average rate for being on a medium or high secure ward.

Given this context, it is not surprising that black patients are also less likely to receive non-coercive treatments such as psychotherapy and counselling than other groups, and more likely to receive higher doses of medication.

It is also not surprising that certain groups of BAME people are more likely to be dissatisfied with their experiences of mental services. A 2003 survey of services users by Rethink found that 88 per cent of black respondents did not agree with their diagnosis compared with 14 per cent of white respondents; and 44 per cent of black respondents were unhappy with the care they received compared with 20 per cent of white respondents. The survey also found that black people are 40 per cent more likely to be turned away than white people when asking for help.

BAME people who belong to additional equality groups, for example older BAME people, gay and lesbian BAME people or those of certain socio-economic status often face multiple inequalities in terms of their mental health.

Depression and suicide rates are high among Asian women, for example, yet services are often not appropriate to their needs. For example Asian women are often placed in mixed sex psychiatric wards, contrary to their religious and cultural beliefs. Young people from certain BAME groups show disproportionate experience of many of the known risk factors for developing mental health problems, including exclusion from school, being looked after by the local authority, offending behaviour, and homelessness.<sup>3</sup>

## Access to services

One of the most significant features of mental health inequalities faced by BAME groups are the barriers often faced in accessing appropriate services, particularly at primary and community care levels.

Where BAME people do seek support before mental health issues become acute, GPs often do not pick up on or correctly diagnose issues. They acknowledge that they feel less involved in the care of patients with mental illness from BAME groups.

Cultural and racial stereotyping is a common experience in the context of assessment and decisions concerning treatment. This influences the types of services and diagnosis BAME people receive. There is evidence that stereotyping of Irish people as alcoholics, for example, obstructs treatment for mental health problems.<sup>4</sup>

Where patients do not speak English as a first language, language barriers can

*Cultural and racial stereotyping is a common experience in the context of assessment and decisions concerning treatment.*

## In some cultures mental illness may have considerable stigma attached to it...

- > cause difficulties, particularly where patients do not have access to good quality interpreters. Interpreting services are often being provided in a context where commissioners have poorly specified contacts with unclear policies for quality assurance, and are unwilling to work with community interpreters with whom patients might feel more comfortable.

Such language issues often result in misdiagnosis, making the assessment procedures unnecessarily stressful, and result in low referral rates for psychotherapy and counselling.

BAME groups may lack awareness of the mental health and other health services available to them. This is particularly true of refugees and asylum seekers for whom culture can also act as a barrier.

In some cultures mental illness may have considerable stigma attached to it, preventing sufferers from seeking help. In other cultures, mental wellbeing may be viewed in a more holistic way, and linked to a person's spirituality. Mainstream services in the UK largely ignore such aspects of mental wellbeing. This can discourage people from BAME communities seeking help, while those who do may be poorly diagnosed.

As considered earlier, people from certain BAME communities are much more likely to be assessed as being dangerous to the public and, as a result, detained. Even within hospitals, the risk that BAME patients present is often over-estimated, the result being that coercive forms of treatment including restraint, seclusion and medication are overused. Such widespread and detrimental experiences linked to mental health services have created fear within certain communities, which deters people from seeking help.

### Criminal justice system

One of the most detrimental outcomes of such barriers to primary and community care services are the high rates of referral of certain groups of BAME people to the more acute end of the mental health system from the criminal justice system. They are also contributory factors in the disproportionate numbers of BAME people with mental health problems in British prisons. In fact, as Deryck Browne from NACRO explains on page 26, the criminal justice system is one of the key pathways through which black and some other ethnic minority groups enter the mental health system.

### Alternative solutions

Since the late 1980s and early 1990s, BAME communities have been setting up their own initiatives to address mental health inequalities experienced by their families and communities. Later on we will look at some case studies which highlight the unique and vital role of these organisations.

### Delivering Race Equality in Mental Health Care 2005

All these inequalities have been the focus of much debate and discussion, particularly over the last 13 years, with resources and programmes being established in response. The most significant programme has been the Department of Health's five year Delivering Race Equality in Mental Health Care Programme (DRE) which began in 2005.

DRE has failed in many of its key aims, with the Count Me In census over the last five years revealing fixed patterns of racial inequality with no signs of improvement. The over-representation of BAME people at the secure end of the mental health system, and under-representation at the primary and community care services end remains the norm.

The higher than average rates of admission for black and mixed black and white groups reported in the 2009 Census are similar to those reported in previous Censuses. Rates of patients subject to the Mental Health Act, including CTOs, are similarly still above average for these groups, as well as the other white group.

The need for continued and targeted work to address these persistent inequalities was highlighted by the Care Quality Commission in reporting on the 2009 Census. It urged statutory bodies to undertake improved local strategic needs assessment, commission fair, personalised and effective services that reduced mental ill-health among ethnic minority groups, and improved care pathways for those who had become mentally unwell.

There are concerns within the BAME sector that this need is not adequately addressed within government's recently launched mental health strategy, *New Horizons*, which does not take forward the work of DRE more than in rhetoric or respond to the abundantly clear evidence showing the continuing need to focus on the specific needs of different communities.

Additionally, there are some concerns that a number of the proposals under the government's new health white paper, *Equity and Excellence: Liberating the NHS*<sup>5</sup>

could potentially be problematic for BAME people with mental health issues.

With proposals to get rid of Primary Care Trusts (PCTs) and hand responsibilities for commissioning to GPs, there are concerns that the latter do not have the necessary skills to effectively commission mental health services, let alone those responsive to the specific needs of BAME people.

A recent GP survey by Rethink discovered that only one in three are ready for a new mental health role.<sup>6</sup> A big challenge for GPs will be to develop a strategic understanding of the particular needs of BAME people with mental health issues, so that they can negotiate with a range of care partners. They will need to develop an understanding of the role of the BAME VCS in addressing these.

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<sup>1</sup> Care Quality Commission (2010) *Count Me In 2009 Results of the 2009 national census of inpatients and patients on supervised community treatment in mental health and learning disability services in England and Wales*.

<sup>2</sup> Nacro (2007) *Black communities, mental health and the criminal justice system*.

<sup>3</sup> Kurtz, Z. and Street, C. (November 2006) 'Mental health services for young people from black and minority ethnic backgrounds: the current challenge'. *Journal of Children's Services, Volume 1 Issue 3*. Pavilion Journals (Brighton) Ltd.

<sup>4</sup> Department of Health (2003) *Inside Outside. Improving Mental Health Services for Black and Minority Ethnic Communities in England*.

<sup>5</sup> Department of Health (July 2010) *Equality and excellence: Liberating the NHS*

<sup>6</sup> Rethink (2010) *Fair treatment now. Better outcomes, lower costs in severe mental illness*.

# Mental health and BAME communities – a national perspective

by Melba Wilson, National Programme Lead, Mental Health Equalities  
National Mental Health Development Unit

The past 20 years have seen significant developments which aimed to improve the position of people from black, Asian and minority ethnic (BAME) communities. This work acknowledged the need to raise the baseline for care and treatment; to work more effectively with people who use services and their families; and to address inequalities as part of a broader context of promoting equality.

In 1999 the National Service Framework for Mental Health (NSF 1999-2009) recognised that services did not adequately meet the needs of BAME communities, and that they lacked confidence in mental health services. It called for planning and implementation, which included partnerships with local communities, service users and carers, to reduce inequalities.<sup>1</sup>

The NSF was followed by and ran concurrently with the Delivering Race Equality in Mental Healthcare Action Plan (DRE 2005-2010). The DRE action plan was a comprehensive framework of action built around three building blocks for change:

- more appropriate and responsive services
- community engagement
- better information

The work was far-reaching and engaged a wide range of partners and networks. These included government departments, local authorities, strategic health authorities, mental health trusts, primary care trusts and others. The work also included relationships with frontline staff and, of course, people from diverse BAME backgrounds.

The DRE programme resulted in a wealth of evidence, which promoted innovation, challenged inequality and helped to address concerns of people from BAME communities. The programme also helped to influence policy and practice for promoting mental health and wellbeing, and addressing inequalities.

This included an emphasis on learning

from the evidence; taking forward work in a single equalities context<sup>2</sup> (to reflect the multi-layered aspects of people's lives); focusing on workforce development; and, importantly, continuing to incorporate and integrate the voices of users and carers in creating change.

## The service user movement

There is a long and historic tradition of developing and building the mental health service user movement in Britain. The legacy of those who developed and campaigned for advocacy and involvement, and who took direct, as well as indirect action to try and achieve change has created a position whereby 'engaging people who use mental health services in developing those services... [or user involvement]... is now an intrinsic part of policy'.<sup>3</sup>

The case for better understanding the complexity and the need for greater inclusivity within the service user movement was set out eloquently by black service users in their report *Dancing to our own tunes: reassessing black and minority ethnic mental health service user involvement*.<sup>4</sup> The report noted that: '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 activities.' Dr Jayasree Kalathil, author of the report, writes more on this topic on page 16.

This represents an additional complexity, which continues to be addressed in relation to user involvement. The 2006 REU report on participation and black and minority ethnic service users notes that 'it is clear that there are a variety of ways to promote user involvement [and that] these need to be adapted and used according to the context, task in hand and the group(s) of service users being engaged with'.<sup>5</sup>



*'social inequalities in health arise because of inequalities in the conditions of daily life...'*

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### Reducing health inequalities as well as promoting equality

The current focus on reducing health inequalities as well as promoting equality provides a useful way forward. This is not only in the context of the need for a socially inclusive approach to enable people to have a say in how mental health policy and practice develops, but also in terms of the wider contribution that communities of diversity and communities of interest can make to society as a whole.

In his strategic review of health inequalities (2010) Sir Michael Marmot emphasises 'reducing health inequalities is a matter of fairness and social justice.' He argues that: 'social inequalities in health arise because of inequalities in the conditions of daily life and the fundamental drivers that give rise to them: inequalities in power, money and resources.'

Furthermore, Marmot notes that 'these social and economic inequalities underpin the determinants of health: the range of interacting factors that shape health and wellbeing. These include material circumstances, the social environment, psychosocial factors, behaviours and biological factors. In turn, these factors are influenced by social position, itself shaped by education, occupation, income, gender, ethnicity and race. All these influences are affected by the socio-political, cultural, and social context in which they sit.'<sup>6</sup>

This is the context which frames the work of the National Mental Health Development Unit (NMH DU), and in particular the work of the mental health equalities programme. The recently published NMH DU Equalities Factfile<sup>7</sup> identifies that in terms of race there is still a great deal of ground to be covered in reducing the disparities and inequalities which continue to exist.

### The Equality Act 2010

The Equality Act 2010 is intended to provide a new crosscutting legislative framework to protect the rights of individuals and advance equality of opportunity for all; to update, simplify and strengthen the previous legislation; and to deliver a simple, modern and accessible framework of discrimination law which protects individuals from unfair treatment and promotes a fair and more equal society.

The Act:

- bans discrimination against adults in the provision of services and exercise of public functions
- creates a public sector duty to have due regard to the need to eliminate discrimination and to advance equality of opportunity and foster good relations between people who share a protected characteristic and people who do not share it

This, then, provides a good framework for continuing to address issues of equality and inequality in relation to race, age, gender, disability, sexuality and faith – both now and in the future.



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<sup>1</sup> Department of Health (2005), *Delivering Race Equality in Mental Healthcare*, an action plan for reform inside and outside services

<sup>2</sup> The single equality context refers to the situation whereby multiple inequalities in relation to the protected characteristics under the law are considered simultaneously

<sup>3</sup> DH 1999, 2005; NIMHE 2003

<sup>4</sup> National Survivor/User Network/Catch-a-Fiya (2008) *Dancing to our own tunes: reassessing black and minority ethnic mental health service user involvement*

<sup>5</sup> REU (2006), Participation Report 14, *Doing it for themselves: participation and black and minority ethnic service users*

<sup>6</sup> *Fair Society, Healthy Lives*, The Marmot Review, Strategic review of health inequalities in England post-2010, Executive Summary (2010) [www.ucl.ac.uk/marmotreview](http://www.ucl.ac.uk/marmotreview)

<sup>7</sup> National Mental Health Development Unit (2010), Factfile 5, *Equalities in Mental Health*

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# Mental health inequalities – a view from the inside

Mental health services for BME communities have come a long way. There has been recognition of the historic inadequacies of the interaction between these services and BME communities, as well as acknowledging the need to increase access to early intervention services within mental health.

by Lord Adebowale CBE, ROTA Patron and Chief Executive of Turning Point

The fear of mental health services from BME communities has created a barrier which prevents people accessing help when they most need it. The results of the 2009 Count Me In census of inpatients and patients on supervised community treatment in mental health services show this fear is somewhat justified. Barbara Nea's article on page 6 discusses this in more detail.

The tradition of both institutional and overt racism has meant BME communities feel less comfortable accessing mental health services. As a result, mental health problems are more likely to become entrenched and have the potential to have a greater effect on the individual.

Mental health is an area of particular vulnerability for BME communities. Those who are sectioned have no power; their futures are determined by others. The perceived vulnerability connected to mental health ensures it is an emotive and political issue. It creates a great deal of fear and misunderstanding while also foregrounding the inequality within society.

Customarily, the emphasis of psychiatry in the West has been overly medicalised. Some people respond best to medication, but in the main there has been an over-reliance on the use of drugs to control behaviour rather than seeking to understand the troubles which are at the root of problematic behaviour.

In contrast, early intervention within mental health problems is empowering. The individual receiving support has to engage with their problems and seek solutions which work for them rather than being a passive recipient of treatment. Early intervention is crucial to ensure greater equitable access to mental health services for BME communities.

Established in 2005, Delivering Race Equality in Mental Health Care (DRE) was a plan to address the discrimination against BME communities within mental health services. It incorporated 12 characteristics which mental health services should embody. Overwhelmingly these can be categorised as improvement in outcomes, greater satisfaction and access of services, as well as improved rates of feelings of recovery for BME communities.

In conjunction with this focus on outcomes was the need to reduce negative experiences within the mental health services for those from BME communities. There should be fewer violent incidents resulting from inadequate treatment of mental illness, a reduction in the use of compulsory detention and challenges to the disproportionate rate of admission of people from BME communities.

The DRE programme has had some positive outcomes in raising awareness of the inequalities that face people from BME

*Early intervention is crucial to ensure greater equitable access to mental health services for BME communities.*



## Overall, my view of mental health services is positive.

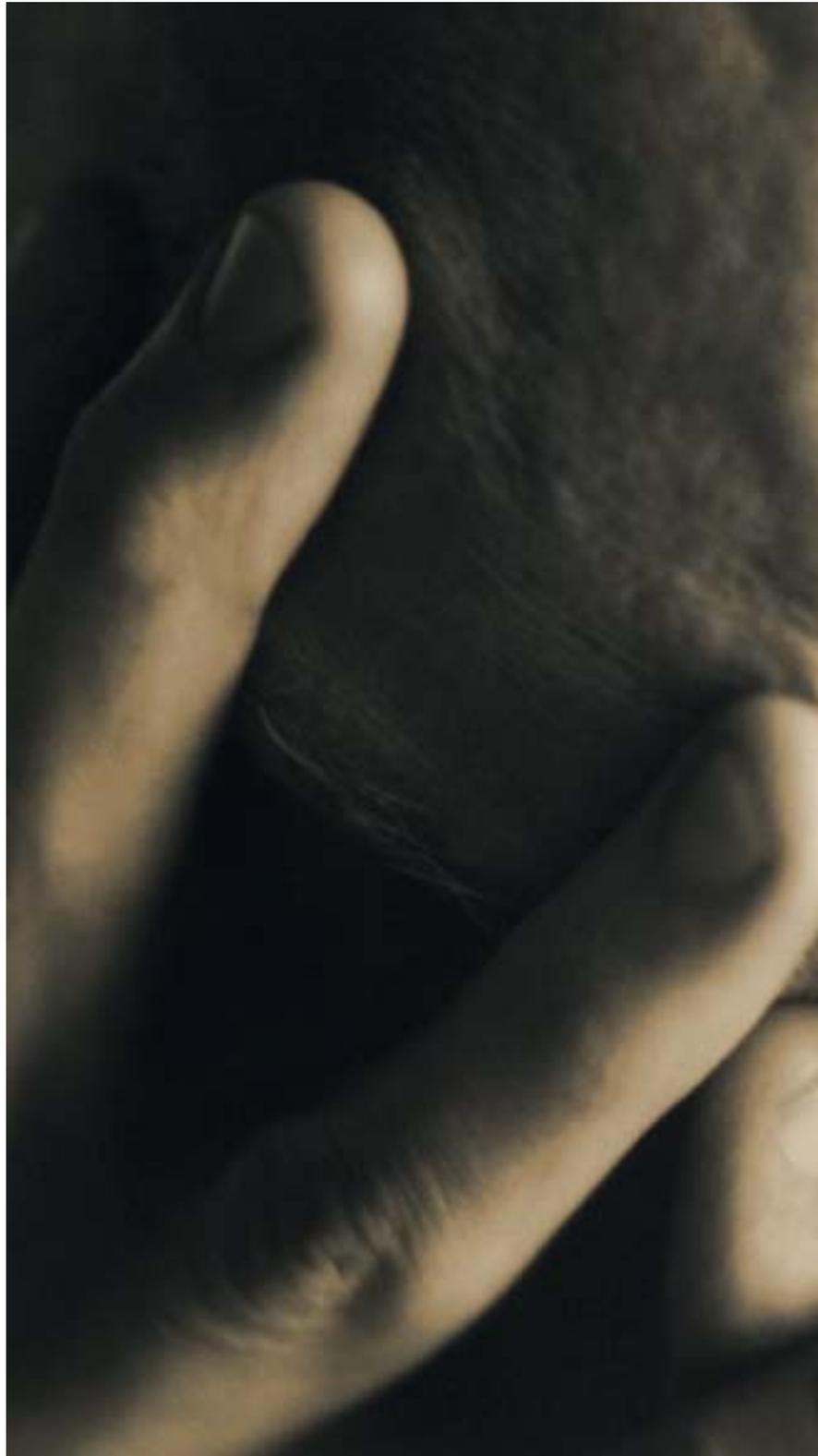
- > communities when accessing services. The Review of the DRE programme indicates little disparity between the experiences of the BME and white British communities in terms of satisfaction and feelings of recovery.<sup>1</sup> Nevertheless, the community engagement projects as part of DRE did indicate an existing level of fear when accessing mental health services. It is this fear that still needs to be addressed to ensure equitable mental health services.

My involvement with DRE was through chairing the BME National Steering Group, a group tasked with helping inform the BME Mental Health Programme Board and the DRE. This experience can only be described as challenging and indicates the difficulties in trying to establish equity in access within mental health services. Three factors contributed to this difficulty:

- The first was the disapproval directed towards me from certain members of the black community who believed that trying to improve the system from within was tantamount to selling out. Rather they would have preferred to see a separate mental health service for black people.

This is something I believe would only serve to create further inequality by acting to reinforce the view that black people accessing mental health services are different from white people. It is not that there is an inherent difference between people – rather that the experiences of people are different. This calls for a change to mental health services so they respond appropriately to the diversity of experience of the people access them.

- The second difficulty was the bureaucracy involved with working with the group. There was a lack of continuity to the group. Obviously political changes to the position of Secretary of State cannot be helped but the changes in the form and related experiences of the group made it harder to get a coherent grasp of the concerns of members and to advise the best way forward for equality within mental health services.





- In conjunction with this was the unwillingness of some within the health service to respond to the DRE. Although there was an obligation placed on strategic health authorities to implement the best practice of the DRE, there was no means of enforcement. Consequently, there was no recourse for strategic health authorities which did not respond to the implementation demands of the DRE. This led to a feeling that some did not take the DRE seriously.

The programme was about achieving equitable access to mental health services, but the experiences of the National Steering Group indicate the difficulty there can be for BME communities to ensure their voices are heard and influence the process of change. Despite these difficulties, I believe that DRE was still a success – something which should be attributed to the hard work of Melba Wilson, National Head of DRE. It has helped to ensure an understanding of the inequities faced by the BME community when attempting to access services.

The spirit of DRE lives on in the New Horizons agenda. This replaced the guidance of the National Service Framework, emphasising the need for wellbeing rather than diagnosis. Mental wellbeing is recognised as being socially determined: it is dependent on our interactions with the wider community. This is a strong rebuttal against those who still claim the differences in access of BME communities of mental health services are the result of biological differences.

Of course it is impossible to attribute direct causation to one or another factor when considering mental health, but certain factors within the experiences of BME communities – the pressures caused by racism and unemployment for example – increase the prevalence of mental health conditions. The New Horizons agenda emphasis on the need for person-centred early intervention incorporates this social account.

The influence of DRE can be seen within the introduction of Increasing Access to Psychological Therapies (IAPT) services within the New Horizons agenda.

IAPT is a model within mental health services which aims to increase early access to talking therapies. This ensures mental health challenges can be addressed as early as possible before they are allowed to get worse and have an increasingly negative effect on individuals.

This preventative focus is something which my organisation, Turning Point, has fully incorporated within our IAPT delivery model, Rightsteps, which seeks to respond to the whole needs of an individual. It offers assessments via telephone and a care pathway is mapped in which the problems the individual faces are addressed holistically. The wellbeing of the whole individual is taken as the focus of the intervention rather than basing care on a diagnosis.

Care can take into account the differences in experiences of each service user which helps to alleviate fear of engaging with mental health services. This results in greater engagement from the BME community. The evaluation of an IAPT pilot site in Newham has shown the positive effect it can have on increasing BME communities' access to early intervention services. The number of BME service users referred to mental health services within the Newham pilot site increased from 614 in 2006 to 1,860 in 2008, suggesting the success of the IAPT model in combating inequitable access to services.<sup>2</sup>

Overall, my view of mental health services is positive. If we consider where they were 50 years ago, there has been definite progress. There are still inequalities and tales of discrimination survive. We must never forget that.

However, there is greater recognition of the difficulties facing BME communities and that the focus of services should be the individual rather than assuming a homogenous BME community. Nevertheless, I am concerned that in-fighting within BME communities will fail to capitalise on the progress within mental health services and the related New Horizons agenda.

We should not let the horrors of the past dictate the future.



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<sup>1</sup> Department of Health and National Mental Health Development Unit (2009) Delivering Race Equality in Mental Health Care: A Review

<sup>2</sup> Ibid

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# New government, the public and the next step in tackling multiple needs and exclusions

Since late 2008 MEAM – formed of Clinks, DrugScope, Homeless Link and MIND – has been working alongside its 1,600 frontline member organisations to help improve policy and practice for people facing multiple needs and exclusions.

by **Oliver Hilbery, Project Director at Making Every Adult Matter (MEAM)**



- > People with multiple needs and exclusions are part of all our communities. They experience a combination of problems in their lives – homelessness, substance misuse, mental ill health and offending – leading to ineffective responses from statutory and voluntary services designed to deal with one problem at a time. As a result they often live chaotic lives, reliant on inappropriate and expensive emergency or criminal justice responses, and without the coordinated interventions that help change lives.

## Making progress

Tackling multiple needs and exclusions requires simultaneous action from frontline services and national government which builds on what we know works across both policy and practice. So far 2010 has been an exciting year on both counts.

In the last few months MEAM has announced a series of coordinated service delivery pilots, commencing later this year, which will develop previous work such as the Adults Facing Chronic Exclusion programme and support MEAM members around this agenda. At a national level there has been the general election (of course) and the publication of a new book *Hardest to Reach? – The politics of multiple needs and exclusions*.

It would have been hard to miss the four weeks of general election campaigning in which the differences between the three main parties were nightly news. But after all those talks the reality of a coalition government highlights that on some issues there can and must be shared ground. Both David Cameron and Nick Clegg would agree for example (as would the opposition) that supporting the most vulnerable, reforming public services so that all may benefit, and tackling the budgetary deficit are important aims for the new administration.

Nowhere do these three aims converge more readily than around people facing multiple needs and exclusions, making policy development for this group an excellent place for the new government to focus its efforts.

As shown by contributions from leading cross-party politicians in *Hardest to Reach? – The politics of multiple needs and exclusions* there is much agreement on the approach that government should take. This includes making multiple needs and exclusions a key policy issue in Whitehall and encouraging coordinated service delivery in local areas without

being prescriptive about the detail.

The new government has a unique opportunity to take the next step. MEAM is calling for it to publish a multiple needs and exclusions green paper early in this parliament to lay out a shared vision and approach.

## The public

The public too think that politicians and local services should embrace change. Findings from a YouGov poll also published in *Hardest to Reach?* make welcome reading. Sixty-eight per cent of people are personally concerned about the problems faced by people with multiple needs and exclusions. Six in 10 recognise the hidden potential of individuals, agreeing that if they 'are given help to improve their lives they will be able to contribute much more to society in the future'. The same proportion recognise the social and economic benefits that will arise from positive, coordinated action, saying that 'if government and local services had a stronger focus on this group and worked better for them it would help improve their situation'.

## Going forward together

This is heartening news. It shows that as the roar of the election fades into history and the real work begins, a bold government working alongside coordinated local services and an aware public, could make real progress. MEAM will continue to remind politicians of the public's support, of the best local services and of the clear links between tackling multiple needs and exclusions and the shared aims of the new coalition administration.

### Find out more

*Hardest to Reach? – The politics of multiple needs and exclusions* was produced by the Fabian Society with cross-party contributions from Iain Duncan Smith (Centre for Social Justice), Hilary Armstrong and Alisdair Murray (Centre Forum). It was published in association with Making Every Adult Matter, supported by the Calouste Gulbenkian Foundation and is available to download free of charge at [www.meam.org.uk](http://www.meam.org.uk).



*Sixty-eight per cent of people are personally concerned about the problems faced by people with multiple needs and exclusions.*

# Beyond tokenism: participation of mental health service users from racialised groups in mainstream user involvement initiatives

by Dr Jayasree Kalathil, a researcher, writer and former user of mental health services

In the annals of psychiatry, Philippe Pinel is often recognised as the originator of humane treatment (*traitement moral*) of those considered 'insane'. Later analysis of Pinel's correspondence and writings revealed that in his formulations of this philosophy of treatment, he was indebted to the insight and opinions of Jean-Baptiste Pussin, a governor of the Asylum de Bicêtre in Paris where Pinel worked. Pussin was a former patient at the asylum.

Pussin believed in several ideas which were ahead of his time – the possibility of recovery, of forming a therapist-patient relationship based on trust, and of the therapeutic values of meaningful occupation and employment. It is in Pussin's answers to Pinel's questions about his approach to care that we find some of the early discussions of what we would today understand as 'user involvement'.<sup>1</sup>

That was towards the end of the 18th century. It took until the end of the 20th century before the idea that those who have direct experience of mental distress and of psychiatric services may have the expertise to inform and influence the delivery of such services, gained recognition in policy. The new agenda for mental health, New Horizons, recognises user involvement as a key part of its strategy.<sup>2</sup> This recognition has come as a result of years of campaigning from mental health service users and survivors.

User involvement is many things to many people, including participation in policy-driven, organisational initiatives, in peer groups for support and capacity building, and in political campaigns. It is generally seen as an enabling process. However, it is true that some groups, especially those from 'racialised'<sup>3</sup> groups, are not as involved as others in mainstream user involvement initiatives.

A common reason given by mainstream user involvement initiatives, and indeed by the Department of Health,

for this perceived 'under-representation' is that we are 'hard to reach'. And yet we continue to be over-represented in mental health services, especially in coercive and compulsory treatment and care, including supervised Community Treatment Orders.<sup>4</sup> Clearly we are 'involved'. But many of us seldom feature in initiatives that involve service users in advisory and decision-making roles.

Several common themes arise from recent studies on the participation of service users from racialised groups in user involvement initiatives.<sup>5</sup> First of all, there seems to be a disagreement about the definition of user involvement.

Participants in a recent consultation felt that the mainstream definition of user involvement – specific activities involving service users, often driven by policy and defined by the organisation setting up these initiatives – did not acknowledge the work that many people were doing within their communities to bring about an understanding of mental health and attitudes towards it.<sup>6</sup> In this sense, rather than thinking about the under-representation of people from racialised groups in mainstream initiatives, we need to start thinking about nurturing and supporting work that is already happening within local communities.

For many people from racialised groups, contact experiences with services have been overwhelmingly negative and discriminatory, involving coercive and punitive measures. User involvement initiatives assume that service users and providers can start working together without addressing power structures and the emotional journeys of service users. Many service users feel that meaningful involvement on equal terms with service providers will not be possible unless there is space to acknowledge and discuss these issues.<sup>7</sup>

The racism and discrimination that

people face in society is often mirrored within mental health services and in mainstream organisations. Being a token 'black' person in an initiative whose structures and parameters are set up in a way that intimidates and silences one's cultural and/or racial identities is a common experience for many people, including this writer.

In mainstream user groups, the pressure to separate one's identity as a service user from one's cultural/racial identity has been keenly felt. Talking about race and racism within user groups sometimes generated accusations of creating divisions within the group. The focus, here, was on user/survivor identities. The tendency was to brush over other markers of identity and experiences, like that of race and racism.<sup>8</sup>

One of the main criticisms about user involvement in general has been that it has not given any real decision-making powers to service users.<sup>9</sup> The hierarchical power structures of the mental health professional-patient relationship are replicated in many user involvement spaces. Merely having some service users around the table is sometimes seen as equality enough. Often, agendas have already been set and decisions made.

Participating as a token representative in these situations can aggravate feelings of disempowerment already felt on account of discriminatory experiences based on one's racial identity, mental health status and position in society. Tew<sup>10</sup> suggests that some service users may be trying to regain some power by making a conscious decision not to get involved, a suggestion borne out by the findings of other consultations.<sup>11</sup>

Despite these challenges, service users from racialised groups have continued to make use of the opportunities available to them. A recent example is the Ambassadors initiative of the Delivering

## We need to start thinking about nurturing and supporting work that is already happening within local communities.

- > Race Equality (DRE) programme.<sup>12</sup> This initiative aimed to 'strengthen strategic involvement in a national forum and work as Ambassadors in shaping the implementation of the DRE Action Plan, regionally and locally' and to provide leadership across its parameters.<sup>13</sup>

The programme brought together regional service user/carer representatives from racialised groups. It is difficult to say what the programme has achieved, especially given the continued over-representation and unacceptable treatment of people from many racialised groups within services.<sup>14</sup>

One clue is the aim itself – service users were expected to be the Ambassadors for a programme whose parameters had already been set up, rather than being involved at a stage when those parameters were being set up and being Ambassadors for the communities and regions they represent.

Research, inquiry reports, personal testimonies and consultations over the years have accumulated enough evidence on how people from racialised groups are treated within mental health services and what changes need to happen. Everyone seems to be convinced that service users from these communities have a key role to

play in bringing about these changes.

If this is true, then it is time to ask some hard questions before wooing more people from these communities into involvement initiatives:

- 1 Is the service/organisation setting up the user involvement initiative convinced that the involvement of service users from racialised groups is necessary for service development? Or is it soliciting their involvement to tick equality assessment boxes?
- 2 Has the initiative set out supportive and safe spaces for discussing people's experiences and emotional journeys if appropriate and necessary?
- 3 Is there a willingness to examine organisational (including clinical) practices and hierarchies?
- 4 What is the service users' role – advising, taking decisions, designing services, consultative? Has clarity been provided about how their contributions will be used?
- 5 Are structures in place to value people's contributions, both through recognition of their expertise and by paying them adequately?

- 6 In non-statutory/user-led groups, does the group provide supportive spaces for the articulation of all identities and incorporate them into work priorities and practices?

The real reason for the under-utilisation of the potential and expertise of service users from racialised groups is the existence of policies and practices that make it hard for mainstream organisations to reach out to communities. If there has to be meaningful and sustained involvement of service users from racialised groups, there will have to be structural changes in power and hierarchies, organisational practices, assumptions about people and communities, resource allocation, the location of decision-making, and the way people are treated within mental health services and outside them.

For more information, please see [www.survivor-research.com](http://www.survivor-research.com).



<sup>1</sup> For a thorough examination of the relationship between Pinel and Pussin and the significance of their ideas for user involvement and recovery, see Davidson, Rakfeldt and Strauss (2010). I thank Dr Suman Fernando for drawing my attention to this discussion.

<sup>2</sup> Department of Health (2009) *New Horizons: Towards a Shared Vision for Mental Health*.

<sup>3</sup> I use the term 'racialised' to refer to groups and communities who are subjected to a range of social, cultural, institutional and psychological 'racialisation' processes by which they are made inferior, seen as different and deficient because of their race, ethnicity, skin colour, national origins, religion etc. For the uses, abuses, problems and possibilities of this formulation see Murji and Solomos (2005).

<sup>4</sup> Care Quality Commission (2010) *Count Me In 2009: Results of the 2009 National Census of Inpatients and Patients on Supervised Community Treatment in Mental Health and Learning Disability Services in England and Wales*.

<sup>5</sup> Kalathil, J (2009) *Dancing to Our Own Tunes: Reassessing Black and Minority Ethnic Mental Health Service User Involvement*. NSUN. Begum, N (2006) *Doing it for Themselves: Participation and Black and Minority Ethnic Service Users*. Blakey, H (2005) *Participation – Why Bother? The Views of Black and Minority Ethnic Mental Health Service Users on Participation in the NHS in Bradford*. International Centre for Participation Studies.

<sup>6</sup> *Ibid.*

<sup>7</sup> Kalathil (2009). Blakey (2005).

<sup>8</sup> Kalathil (2009).

<sup>9</sup> Trivedi, P (2008) 'Black service user involvement: rhetoric or reality?' in *Mental Health in a Multi-Ethnic Society*, edited by S. Fernando and F. Keating. Routledge. Carr, S (2004) *Has Service User Participation Made a Difference to Social Care Services?* SCIE.

<sup>10</sup> Tew, J (2005) 'Power relations, social order and mental health.' in *Social Perspectives in Mental Health*, edited by J. Tew. Jessica Kingsley.

<sup>11</sup> Kalathil (2009).

<sup>12</sup> Department of Health (2005) *Delivering Race Equality in Mental Health Care: An Action Plan for Reform Inside and Outside Services*.

<sup>13</sup> <http://www.nmhd.org.uk/our-work/mhdp/delivering-race-equality/dre-ambassadors/> [Accessed 4 June 2010].

<sup>14</sup> Care Quality Commission (2010).

# Canerows and Plaits: an summary of its recent evaluation

This article presents a picture of Canerows and Plaits, a group run by and for mental health service users with a Black and minority ethnic heritage. An evaluation of the group was completed in April 2010.

by Dwight Reynolds, Secretary of Canerows and Plaits, and a visual artist attending Sound Minds

## Introduction

Canerows and Plaits is a service user-led group based at Sound Minds, a mental health arts project in Battersea, south London. It aims to improve the experience of mental health service users from Black, Asian and Minority Ethnic (BAME) backgrounds both in the community and on the Wandsworth wards of Springfield Hospital, Tooting and Queen Mary's Hospital, Roehampton. Although the group has a BAME focus no one is excluded from the service because of their ethnic background.

The group's activities focus on two methods of engaging service users. The first is by holding meetings every six months called Have Your Say Forums. BAME service users meet health professionals, volunteers and carers to discuss issues, listen to guest speakers and exchange views. These events always have music and food as part of the proceedings.

The second is the Ward Visiting Service, which has the aim of supporting people on the wards by showing them

kindness, compassion and understanding while also ensuring their cultural needs are addressed. The fact that the visitors are of BAME heritage with experience of staying on the wards helps them to relate to people who are receiving the service.

Canerows and Plaits is governed by a steering group made up of four service users (including the author), the Chief Executive of Sound Minds, and a community development worker employed by South West London and St George's Mental Health NHS Trust to work with BME groups.

## About the evaluation

In 2009 Canerows and Plaits received funding for the first time enabling them to carry out the ward visits and Have Your Say forums. The aim of the evaluation was to get feedback from the individuals involved – service users on the ward, ward staff, ward visitors and trainee visitors – so we could get a clear picture of what was working and to make changes where necessary. If the organisation is to grow

and develop it needs to take stock of how things are, gather information and correct its course in line with its aims. Just as important was the need to show our two funders, NHS Wandsworth (the Primary Care Trust) and Grassroots Grants, that our activities were achieving their purpose.

We used an approach to the evaluation known as Participatory Action Research (PAR). This 'involves all the relevant parties actively examining current action in order to change and improve it... It aims to be active co-research by and for those helped... Those being researched determine the purposes and outcomes of their own enquiry'.

An evaluation sub-group was formed to oversee the process, holding meetings once a week from September 2009 to March 2010. The group included Devon Marston, Chair of Canerows and Plaits, Coral Hines, Vice Chair, Dwight Reynolds, Secretary, Rima Williams, Project Co-ordinator, and Patience Seebohm, an independent researcher working with us on her PhD.

Patience helped to coordinate the process and at the end of it synthesised our findings into a report that is informative, balanced and detailed (Reynolds and Seebohm, 2010). This systematic approach gave us a clear picture of the organisation as it stands now which we can use as a guide on how to proceed, and a vision of what the service could be in the future.

To begin the evaluation we needed to do some background research to find out why a project like Canerows and Plaits is needed. This involved studying published literature on BAME mental health issues and local statistics on the ethnic breakdown of mental health service users for the year 2008-09. These figures were compared with those of the general population of Wandsworth. The findings confirmed our belief that BAME people – particularly Black Caribbean and African – are over-represented in the psychiatric system and stay longer within it.



L TO R: DWIGHT REYNOLDS,

RIMA WILLIAMS, CORAL HINES

AND DEVON MARSTON

*“The report from the patients, some of the patients, has been very tremendous .... So far I haven’t received any bad feedback from anyone.”* **Ward Manager**

### > **The evaluation process**

We used the BAME mental health community development worker, Ermias Alemu, as a link in getting consent from senior managers at the mental health trust to conduct the evaluation interviews with staff and service users in the wards.

The information gathering was done by four members of Canerows and Plaits, two external service user researchers and the independent researcher. Interviews took place with 10 service users on the wards, five ward staff, three Visitors and two trainees. Staff and visitor interviews were recorded, fully transcribed and checked by the interviewees.

Staff and service users were asked what had gone well in their opinion, and what could be improved. They were asked whether they thought the Visitors’ BAME background and service user experience made any difference to the service they provided, and they were also asked whether the service should be continued. The partnership between staff and Visitors was also examined to find out what was going well and what could be improved.

Visitors were asked similar questions,

plus their reasons for doing visits and whether they derived any benefits themselves. They were also asked what they enjoyed about the visits and if there were times that were not so good. Feedback forms were filled in by those people attending the Have Your Say Forums. Monitoring data from the visits and forums was gathered and analysed.

There were some problems gathering the data including a virus forcing one ward to close and the refurbishment of another. There was also the difficulty of service users being discharged before they could be interviewed and some being too ill to be interviewed.

### **The findings**

Overall, the findings were wholly and totally positive from all the service users and four of the staff interviewed on the wards. The fifth member of staff was not familiar with the service. Staff were glad that no one was excluded on grounds of ethnicity and most staff also felt the Visitors’ BAME heritage was important. Staff also reported that the ward was

often busy but even when it was at its most chaotic, the Canerows and Plaits Visitors had a sense of calm about them as they engaged with service users.

The Visitors themselves also benefited from the experience of helping others. They are driven by the idea of using their personal experiences of being on the wards to serve others, giving human kindness, compassion, hope and encouragement.

The only slightly negative feedback from the wards was that the visits were not for long enough (one hour per ward per week) and both staff and service users wanted more of them. Communications with staff and within staff teams could be improved. All agreed that the service should continue and that the funding should be renewed.

Feedback from the Have Your Say forums was also positive. All participants (except one) were pleased they could have their say and found the meetings interesting and enjoyable. At one Forum a Ward Visitor spoke about the lack of appropriate hair and skin care for black people on the wards, and a senior manager from the mental health trust undertook to make these products available on all the wards. This showed how well the ward visits and the Have Your Say Forums can complement one another for the benefit of service users.

## **Some of the staff quotes taken from the Evaluation Report:**

*“The report from the patients, some of the patients, has been very tremendous .... So far I haven’t received any bad feedback from anyone.”* **(Ward Manager)**

*“They (the Visitors) come and engage with everyone so even though it’s a BAME initiative there’s no sort of discrimination with anybody.”* **(Staff Nurse)**

*“They come in with this calmness and smiling and I think the way they present themselves just gives the patient that welcoming feeling.”* **(Support Staff)**

Service users on the wards also spoke enthusiastically about the Visitors, their warmth and the positive impact they made. Two service users said that the Visitors brought them love while others spoke about the hope, encouragement and fun that they engendered.

*“I think they are absolutely fantastic!”* **(Service user)**

*“They can empathise with what you are going through.”* **(Service user)**

*“I prefer Black visitors, a Black person will deal with racism more sympathetically.”* **(Service user)**

*“They took the time to listen and helped me to be optimistic, they give encouragement and hope.”* **(Service user)**

The Visitors themselves also benefited from the experience of helping others. They are driven by the idea of using their personal experiences of being on the wards to serve others, giving human kindness, compassion, hope and encouragement.

*“I want to pass on my experience of being on the ward from a different perspective... and also to support patients and help them... look towards being discharged... to give hope really.”* **(Ward Visitor)**

*“I just feel like a million dollars! On that ward, I look at how other people are, I think about myself when I was in that position, and I feel like I’m giving something back because I’m not in that position any more... It’s a two way thing you know, because I get great satisfaction from doing the ward visits.”* **(Ward Visitor)**

*“It makes me feel elated... seeing people from a state of being very unwell and to getting well, seeing the transformation of them, it’s a miracle, it is like a joy.”* **(Ward Visitor)**

## **Conclusion**

The evaluation was a learning experience for all the members of Canerows and Plaits, and we are now following up many of the issues it raised. We hope that it will help us to get funding to continue the work beyond August 2010 as everyone involved in the evaluation felt strongly about the important role BAME service users could play in the delivery of mental health services. They can make a real contribution by improving the experiences of their peers and helping to meet their specific needs.

### **Find out more**

Contact Rima Williams or Devon Marston on 020 7207 1786  
Email [canerows@soundminds.co.uk](mailto:canerows@soundminds.co.uk)

### **Acknowledgements**

Ward Visitors: Coral Hines and Devon Marston  
Project Coordinator: Rima Williams



# After the Bennett case – perspectives and solutions

Almost 12 years ago David ‘Rocky’ Bennett, a 38-year-old African-Caribbean patient in a medium secure psychiatric unit, died after being restrained by staff. Although the incident itself was horrific, perhaps even more significant was the wider resonance it had amongst black and minority ethnic (BME) communities about the way they perceived the mental health system.

by Alison Cobb, Senior Policy and Campaigns Officer, Mind

In response to this tragic event, and the ethnic inequalities in the mental health system that it highlighted, the government produced the five-year *Delivering Race Equality* (DRE) programme which ended this year – working to realise a set of ambitious yet vital goals.

Another legacy of the previous government was its development of a shared vision for mental health – *New Horizons* – a strategy for improving the mental health and wellbeing of the population, and the quality and accessibility of services for people with poor mental health.

This identified two key challenges for reducing the mental health inequalities among some ethnic groups. For commissioners, it was ‘the duty to understand, respect and meet the needs of the BME population, including refugees and asylum seekers’. Here the strategy document highlighted the need for proactive work with communities and the third sector. For public mental health initiatives it was to ‘ensure as a priority that activity supporting good mental health and wellbeing is targeted at, or is at least equally effective for, ethnically diverse populations’.

Mind’s concern about the ending of the DRE programme was that it would leave no substantive challenge to the drivers of ethnic inequality in rates of mental health problems, and in access to and experience of mental health services. The annual *Count Me In* census which formed part of DRE shows continuing BME disproportionality in hospital admissions and the use of compulsion, with those of multiple heritage most likely to be over-represented.

In last year’s *New Horizons* consultation we highlighted three factors affecting race inequalities:

- the different community perceptions of, and responses to, mental health issues

- the challenge of accessing services that often are not built around the particular needs of certain BME populations, particularly asylum seekers and refugees
- the fact that certain racialised groups are more likely to be perceived as dangerous. This is of critical importance when assessing risk as occurs when deciding to apply the Mental Health Act

We called for a clear route map to sustain the successful grassroots initiatives instigated by DRE and achieve the strategic successes that DRE failed to attain. We are currently researching the views of all those involved in DRE so that we can campaign to make sure that the right decisions are made to improve the experience of people from all ethnic backgrounds when they seek help from mental health services. DRE was a first step but the approaches it developed need to be incorporated into all the strategies which have a bearing on BME wellbeing.

Mind’s hope now is that the government will build on the consultative and evidence-based work already carried out through *New Horizons* to develop a practical, long-term strategy for realising the consensus vision that it set out – with a high priority on race equality.

Where does this leave the BME third sector, particularly those working in mental health?

The overriding challenge for the sector as for the new government is the economic one. The value for money provided by third sector services, the specialist knowledge and expertise in BME organisations, and the government’s commitments to reducing health inequalities and devolving power to communities could all augur well for the sector.

However, local empowerment could also disadvantage less popular issues such as mental health and minority groups. Most critically, the sector has to remain in existence to fulfil its potential in these challenging times.

That potential is extensive. In addition to providing tailored services, including advocacy, befriending and advice, community organisations’ expertise is critical to commissioners and policy makers. Cultural competency is now recognised as an essential part of providing effective and appropriate mental health care.

Competence relating to different aspects of cultural diversity is a priority for implementation in the NICE 2009 Schizophrenia guideline, but how extensive is it, and how far has clinical thinking and decision-making been influenced? Lobbying – difficult though it may be for struggling local services which are busy focusing on their clients – is necessary for getting BME issues included in local and national strategies.

Marcel Vige, our Diverse Minds manager, has argued that concerted engagement by BME organisations and service users in strategic development both locally and nationally is essential for the future existence of the BME community sector.<sup>1</sup>

Mind’s approach is to mainstream race equality issues within the organisation while maintaining a focus of expertise and networking through Diverse Minds. Diverse Minds’ work with refugees and asylum seekers illustrates the value of partnerships and exchange between mainstream and specialist BME organisations. Project workers spent a year talking to 150 refugee community groups in England and with service providers across England and Wales to find out the mental health needs of refugees and asylum seekers.

## Cultural competency is now recognised as an essential part of providing effective and appropriate mental health care.

- > The research report, *A civilised society*,<sup>2</sup> sets out the many challenges refugees and asylum seekers face accessing mental health services in England and Wales. They included language barriers, lack of cultural awareness and culturally appropriate services, restrictions on healthcare for refused asylum seekers in England, gaps in service provision such as limited availability of specialist services for those who have experienced torture, and lack of help for refugee children and young people.

The voluntary sector was having to fill gaps in statutory provision despite being overstretched and underfunded, and there was not enough collaboration between the voluntary sector and refugee community organisations. There was still a lot of variation in access to GP services, and access to secondary mental health services did not take account of the needs of refugees.

Many people with severe mental health problems were in detention centres and the mental health care they received was inadequate to respond to the high levels of distress of detainees. Refugee and asylum seeker mental health service providers were struggling to meet demand – and finding it harder to get funding – while mainstream voluntary sector mental health organisations were not accessed much by refugees.

As well as making recommendations, the report describes a number of solutions. Here are two examples:

### Solace, Leeds

Solace is a charity which provides free counselling, psychotherapy and advocacy in the Yorkshire and Humber region. In addition to a senior therapist they have a number of experienced volunteer counsellors and advocates who have been trained to work with the very particular needs of refugee and asylum seeker clients. They use interpreters for counselling to overcome the language barriers. Interpreters are offered training and support to ensure they have the skills to work effectively in a therapeutic setting.

### The Somali Advocacy Project, Mind in Harrow

The project was set up in partnership with a refugee community organisation, 'The Horn Response Project' founded by the Somali community to provide advice, information, advocacy and interpreting to people with mental health problems. In order to expand the project they approached Mind in Harrow with a view to bid jointly for funding.

Together they set up an advocacy service to help people access mental health services; combat the stigma of mental health and fear and mistrust of NHS services; and improve the cultural awareness of mental health professionals; eg the need to take account of the role of religion and family in treatment approaches.

The advocate is Somali and he acts as a bridge or cultural broker between mental health services and the individual and their family. He also provides support with practical issues and helps people experiencing mental distress get in touch with family members. Relatives have often lost contact because of the stigma around mental health and their perception that it is an incurable condition. A large part of his role is explaining the mental health system to people with mental health problems and their families and encouraging trust and understanding between patients and mental health professionals.

Alongside this research, the project worked with advocates from refugee community organisations to develop a robust form of mental health advocacy, *Improving mental health support for refugee communities – an advocacy approach*.<sup>3</sup> This includes not only focused support for individuals, but also advocacy for the community as a whole. The aim was to create a dialogue with the community on issues of mental health (including stigma) and to engage with primary care trusts and other provider agencies to develop community-focused services. Between improving awareness of local mainstream providers and helping equip refugee community advocates to navigate the mental health system, this work has

demonstrated how to break down barriers.

Another key issue for Mind is the availability and quality of Independent Mental Health Advocacy services for people from BME communities, specifically for people detained under the Mental Health Act or discharged onto a community treatment order. Nationally, Diverse Minds lobbied for specific BME services to ensure effective advocacy for people at this very sharp end of the mental health system and is now investigating what is happening in practice and feeding it into the Mental Health Alliance's assessment of the mental health legislation.

We urge BME organisations and individuals concerned about mental health to join Diverse Minds and/or the National BME Mental Health Network based at the Afiya Trust.

Lend your voice to these national campaigns and strengthen the sector's voice.



<sup>1</sup> Diverse Minds magazine, winter 2009

<sup>2</sup> Mind, 2009. Download the report at [http://www.mind.org.uk/campaigns\\_and\\_issues/report\\_and\\_resources/2366\\_a\\_civilised\\_society\\_mental\\_health\\_provision\\_for\\_refugees\\_and\\_asylum\\_seekers\\_in\\_england\\_and\\_wales](http://www.mind.org.uk/campaigns_and_issues/report_and_resources/2366_a_civilised_society_mental_health_provision_for_refugees_and_asylum_seekers_in_england_and_wales)

<sup>3</sup> Mind, 2009. Download the report at [http://www.mind.org.uk/campaigns\\_and\\_issues/report\\_and\\_resources/2367\\_improving\\_mental\\_health\\_support\\_for\\_refugee\\_communities-an\\_advocacy\\_approach](http://www.mind.org.uk/campaigns_and_issues/report_and_resources/2367_improving_mental_health_support_for_refugee_communities-an_advocacy_approach)

# Making our voices heard – three case studies

BAME organisations have a unique place within their communities addressing mental health inequalities. They:

- provide services to meet needs that mainstream providers are either unaware of or do not have the expertise to address. They may also bridge the gap between BAME communities and mainstream services
- empower BAME communities and support their engagement in service and policy development
- tackle the wider socio-economic determinants of mental ill-health

Despite this they are undervalued and under-supported. The general picture presented by existing regional and national research is that these specialist groups remain relatively fragile, suffering from a substantial lack of capacity due to severe under-investment and access to adequate



infrastructure support.

Many BAME organisations struggle to grow and develop and even to sustain their operations. They operate in an increasingly challenging environment. The recession is having a disproportionate impact on them, and the move from grant making to commissioning is favouring large and more resilient mainstream voluntary and community (VCS) organisations.

In this section, we feature three organisations which provide critical support and services to their communities. CAIA has given a focus for London's Armenian communities for nearly 25 years. Likewise, Camden Chinese Community Centre has been an integral part of the local area for a similar length of time. Finally, Tageero is less than 10 years old, and working with BAME people of Somali origin.



# Homeland or hostland? a view from the Centre for Armenian Information and Advice

> Misak Ohanian, Manager of the Centre for Armenian Information and Advice (CAIA) started the Centre in 1986 to address the personal needs of the Armenian communities in London. The relatively small population of 20,000 is scattered across the city and finds a base in west London at Hayashen.

CAIA exists to improve the quality of life for Armenian people. Originally they provided information, advice and advocacy for refugees, women, older people and their carers but are now the focal point for all of London's Armenian communities. They address issues such as health, welfare rights, immigration and housing, and also offer social and cultural events for all age groups.

Armenian communities are complex because they include nationalities from many troubled parts of the world including Iraq, Iran, Lebanon, Turkey and the former Soviet Union. More Armenians live outside Armenia than inside, due to centuries of massacres and persecution. A diaspora within a diaspora has been created as a result of dispersions followed by further dispersions across the world. Consequently there is no such thing as a homogenous Armenian community.

It can be difficult for two Armenians to communicate. They have commonalities, for example their shared history, faith, and language. But there are also differences in terms of how long they have been in the UK, whether they speak English, and whether they have been assimilated or integrated. All these factors have an impact on mental health.

Misak says: "mental wellbeing is a living, breathing issue for us. There is very little research available about the Armenian mental state and the continuing trauma of Genocide denial. Experiences are passed on from generation to generation. Older people live all their lives in one place. They suddenly have to adjust to living in a completely different place with language difficulties."

Likewise, younger people with a dual heritage may not feel 100 per cent at home in the UK, and there are Armenians in 120 countries all feeling the same way. So they may not be totally mentally well. As Misak says: "They can be living collectively in a state of fragmentation, and individually with multiple identities, suffering at the same time from a lack of identity."

That identity has been forged by many events and people – so there are a complex set of reasons why someone behaves in a certain way. Last year CAIA helped people from 19 different countries. Different waves of migration mean that each group has a different way of dealing with things.

For example, some people become assimilated into the British way of life and stop thinking of themselves as Armenian. Others choose to embrace their cultural identity and become integrated, maintaining a dual heritage. This is the concept of homeland or hostland. Some Armenians have come to see the UK as their home; for others it is still a host country.

Mental health issues are considered taboo within this group of people. Misak

says there is a lot of depression and loneliness because Armenian groups are so disparate and disempowered. Day to day survival is difficult and he has known of refugees and asylum seekers who have committed suicide because they felt unable to cope.

One of the barriers to accessing mainstream mental health services for the Armenian communities is language. But it is about so much more than language alone. CAIA provides a social space where people can find out about services among people who understand their needs. The existence of the organisation also acts as a protective factor against the development of certain mental health problems. A mainstream, non-Armenian organisation would find it difficult to offer the same special level of care and genuine feeling.

CAIA employs a health advocacy worker, Hrachik Sarian, who supports people both within the Centre and outside. On a visit to CAIA to meet clients and staff, it was clear that her work is vital to the continued good health of the people she cares for. However, funding for her post is in place only until March 2011.

There are now also bi-monthly mental health surgeries at the Centre run by the West London Mental Health Trust for which CAIA provides interpreters. Clients are comfortable discussing their problems in this safe space where they are not in any other setting. One person said this is the only place her mother will talk about her feelings. In this way staff are able to pick up on any underlying mental health problem when another issue – for instance, housing – is the presenting problem.

The older people and their carers we spoke to were unanimous in their praise for CAIA and Misak's work. One carer told us that the Centre and the church are the only places her mother visits. If CAIA did not exist, her feelings of isolation would be increased. Others know that there would be more mental health problems. It gives them a feeling of safety, an understanding of their problems and all-important human contact, when the Armenian presence is often invisible to decision makers, and its voice unheard.

**Misak Ohanian's** own story is a living example of how an Armenian identity is forged. He was born in Cyprus where his grandparents had fled following the Armenian genocide. In 1963, both his parents and grandparents had to leave Cyprus when it divided, and came to the UK. For the second time in his life, Misak's grandfather had lost everything.

In the UK, Misak rediscovered his roots and relearned Armenian. The development of CAIA has mirrored his life: he started the elders lunch club to enable his parents to meet their peers and celebrate their culture. When his son was born, so was the playgroup.

He says: "We have always been involved in fundraising and community activities. My mother still cooks for the elders club and recently gave a cookery class. We've developed some intergenerational work and took part in a pilot project last year funded by Acton Together. Getting young and older people together to learn from one another has been very successful."



# Camden Chinese Community Centre – the holistic service

- > Housed in an elegant Grade 2 listed building on the edge of Bloomsbury, the Camden Chinese Community Centre has been serving local Chinese people since 1981.

The Centre provides an elderly programme, looking at social issues, nutrition and health; needs assessment and advocacy; a housebound project for domiciliary care of local Chinese elderly and disabled people; an advice service for issues including immigration, welfare benefits and domestic violence; and a bilingual nursery programme for children under five which is unique in London. Non-Chinese people use the Centre's services, as they want their children to learn Chinese. This demonstrates the key role this organisation can play in community cohesion.

Lincoln Lim, the Centre's Director, describes their services as holistic. "For instance, we go with a social worker and act as interpreter. One of the key problems with using an external interpreter is that they don't know the case. We're best placed to get into the real issues and have real impact", he says. "If we see someone's in unsuitable accommodation, we can work with social services to move them somewhere more appropriate."

An outsider might find it hard to

understand why a Chinese-led organisation is best placed to work within its own community. There is an intrinsic and unspoken language between Centre staff and the people they help. Someone will open up even a little to someone who understands their needs in a culturally-sensitive way, but is more likely not to admit to a problem when someone from a mainstream organisation asks the same question.

The Centre has identified large numbers of elderly people suffering from depression. Their needs assessment worker is very skilled and experienced in spotting the signs and symptoms and follows up on these mental health needs. They may alert a doctor to do a further assessment and provide suitable medication, and also give practical help, for example transport to the Centre to do daily exercise, have lunch and meet other people. "We provide the whole package – including spiritual help. People do get better", says Lincoln.

The language barrier can be a big issue and compounds isolation – a very real mental health problem for many elderly Chinese people. There is a sheltered housing close by which has 80 per cent Chinese residents. Centre volunteers provide 'meals on feet', taking a good, healthy lunch round to people who used to attend the Centre when they were mobile. This helps to maintain contact and provides nutrition for people who otherwise might not bother.

Lincoln is concerned about personalisation and the effect it could have on his organisation and the community it serves. The London borough of Camden knows the price of the Centre's services, what it includes and that staff are properly trained and qualified. They are monitored and were recently awarded 'three star excellent services', by the Commission for Social Care Inspection. He worries that if their service seems higher in price than another provider's, people will opt for the cheaper version without understanding that the level of service will not be the same.

"No one's talking about the underlying issues. If personalisation isn't used correctly, what will the impact be? There's no discussion about monitoring, and others might not be as good. It's easy to exploit elderly people who don't understand the language", he says.

The other issue is that of the Centre's size. He feels that they are being forced to compete with larger organisations which have big marketing budgets. And of course

it is not the elderly person who looks for services, but the family on their behalf. However, the Centre is well placed to offer appropriate Chinese services, speaking Mandarin, Cantonese and other local dialects which cater for older and younger age groups. Lincoln feels that there should be a way of linking up with larger groups to bid for tenders across London, as he believes local councils know which delivery organisations provide the best services. He also plans to make the most of the opportunities which personalisation can offer by developing the website and other marketing initiatives.

The Centre participated in the test bed for 'Better Care Choices', the personalisation project in Camden. The self-assessment is very complex and takes a long time. Yuk Lin Tan, who helped a number of clients with these forms, says: "They're very difficult for people who don't understand the language as the choices are very subtle. If you don't tick the right boxes your score will be low and your money and hours will be cut as a result. The people involved were very anxious. Some of them are in their 80s and 90s, so concentrating for two hours was very difficult."

The idea was that university students would help vulnerable people to complete the forms but Lincoln and Yuk Lin also identified a problem here in that the students would not have the understanding of individual cases to interpret responses.

Maybe an answer would be to use the youth group which runs on a shoestring as funding was cut about three years ago. The funders' view is that there are no problems with Chinese youth as they are generally a high achieving group in school.

Lincoln argues that the Centre's activities for young people – homework clubs, intergenerational work, object handling with the British Museum and visiting the elderly in sheltered housing – actually pre-empt any potential problems. In a way they are being disadvantaged by their own success.

The Camden Chinese Community Centre is truly embedded in the local community. Perhaps Big Society will give new impetus and opportunities for its important services.



The Centre was founded by **Lincoln Lim's** mother. When he took early retirement after 30 years in business, he was encouraged to become a trustee and came into the Centre one day a week. "Then the Board asked me to chair the building committee to look at restoration and fundraising – neither of which I knew anything about – and that's how it started", he says. He has been Director for 18 months, overseeing trebled turnover, increased profit and a reduction in the building's mortgage.

**Yuk Lin Tan** was a manager at the Centre, and rejoined as Lincoln's assistant after maternity leave.

# Tageero – giving help and support to the Somali community

- > Tucked away in the residential streets of Hillingdon are the premises of Tageero – an organisation dedicated to helping the Somali community, the largest BAME group in the area.

Mustafa Aden manages Tageero (the name means ‘help’ in Arabic and ‘support’ in Somali) in a deprived and disadvantaged area where 80 per cent of the community is on income support.

Started in 2002, Tageero provides responsive and appropriate services and information for BAME communities and anyone with an asylum seeker background. As part of the DRE programme, there is a community development worker who liaises between clients and GPs, mental health services and the local PCT, while also tackling discrimination in mental health services for BAME people by sharing best practice and improving information. However with the ending of the programme, there is no longer any national support available for this initiative.

Tageero continues to facilitate access to other health services by providing interpreters and supporting community development. “About 80 per cent of GPs in this borough are Asian-speaking, but there weren’t any who spoke Somali”, says Mustafa. Now the PCT has recruited one.

Overcrowding is common with six or seven children in a two bedroom house, and unemployment and social exclusion take a toll on the mental health in this community. Tageero ran a three year employment project which ended in February 2010. In total 69 people were helped into employment (mostly at Heathrow’s T5), although 16 have since lost their jobs.

“In my view, social problems are causing mental health problems”, says Mustafa. “In 2007 there were over 100 people with serious mental ill-health, but more than 600 who suffer from long term depression and social exclusion. They don’t attend any of our activities, and there are many people who are severely isolated. One man asked me to send him back home, but it’s not possible. He’s severely mentally ill, but doesn’t want to talk to me or access services here.”

Somali women suffer more mental health problems. They tend to be more vulnerable than men as they may be lone parents struggling with children and often



**Mustafa Aden** was brought up in Norway where he trained as a social worker. He moved to the UK in 2002, first working as a probation officer in the London borough of Harrow. He subsequently moved to Hillingdon, and joined Tageero in December 2004 as Manager.

do not have family around or any activities they can access. Mental health has a particular stigma for mothers.

People are afraid of accessing mental health services because their family believes they will never return. They have seen the effects of medication like muscle wasting and Parkinson’s symptoms and are worried. Tageero runs many awareness sessions which explain how mental health services work. One man who uses community mental health services and has been in hospital told Mustafa how much he had benefitted from his treatment. When Mustafa asked him to talk about his experiences, he believed he would be stigmatised if he spoke about it more widely.

When people start to become mentally unwell, they tend to chew Khat more heavily and drink more. Currently Khat use is legal in the UK, although the government has pledged to ban it. If the family has money, they take their relative to somewhere like Egypt where Khat does not exist, and seek spiritual help. There appears to be little help from statutory or mainstream services to help those who are on the verge of becoming mentally ill because of Khat. Mustafa knows the community is suffering.

Talking therapies are problematic for the Somali community: people do not believe it helps them, and having to use interpreters means information is not transmitted or received properly. However, Tageero is helping three people to become counsellors which will help

direct communication.

Tageero employs four staff and has 11-14 volunteers a month helping both at the project and in outreach work. Despite its small size, 1,060 individuals were helped overall in 2009. There were about 3,000 contacts or interventions over the year, although not all were for mental health issues. On average the outreach team helps 15-23 people a day to access and register with GPs. But as Mustafa says: “my staff attend assessment meetings. Interventions account for 12 hours a week. This doesn’t cover even one per cent of the problem. The scale of social problems has multiplied over the last nine or 10 years. Where the community was about 500 to 750, it’s now 9,000.”

Tageero’s existence is reviewed on a yearly basis which makes it feel quite unstable. “I believe the community would suffer more if we weren’t here”, says Mustafa. “We feed information and survey results back to the PCT and I’m able to sit on the borough mental health committee because of it.”

*The language barrier can be a big issue and compounds isolation – a very real mental health problem...*

# Black communities, mental health and the criminal justice system

by Deryck Browne, NACRO Mental Health Unit





Consecutive research studies and data monitoring consistently show that of all the Black and Minority Ethnic (BME) groups in Britain, those from Black communities in particular, are disproportionately represented in both the mental health and criminal justice systems. This anomaly, for it must be seen as such, is compounded by and can often mask the fact that both systems seriously disadvantage Black people who fall within their remit.

It is surprising how little progress has been made in addressing this important subject. Ministry of Justice statistics arrive with a caveat that disparities and disproportions in the figures 'should not be equated with racism as there are many reasons why disparities may exist'. But the scale and the persistence of the discrepancies mean that they are impossible to ignore.

These statistics bear out year upon year the discrimination experienced by Black people who come into contact with the criminal justice agencies. At the same time the Department of Health has conceded that there remains an undue emphasis on coercive models of treatment for Black mental health patients with organisational requirements often taking precedence over their individual needs. That there are such high numbers of Black people coming into criminal justice settings, coupled with the discrimination they may face once they are there can result in the criminal justice system acting as a gateway to the mental health system for Black offenders.

Hence, the interface between the two systems is of crucial importance. And the concept of diversion, whereby schemes, usually court based, facilitate the early detection of people with mental health problems and attempt to ensure appropriate outcomes must necessarily take on a slightly different dynamic when it comes to provision of services for BME groups.

These trends are not new. Historically higher proportions of Black (particularly young) people have been more likely to be stopped by police, arrested and once arrested less likely to be cautioned. Similarly, Black people have been more likely to be remanded in custody, more likely to plead not guilty, and where found guilty more likely to receive longer custodial sentences than their White contemporaries. Even before coming to trial, an analysis of 13,000 case files carried out by the Crown Prosecution Service

found that there were more likely to be objections to bail for Black males than for White males.

Figures such as these reveal that the disproportions continue through each stage of the criminal justice process from initial contact right through to sentencing. There are indeed various criminological explanations for the cause of this anomaly including discrimination by the police and socio-demographic factors. There is even the theory that as Black people are more likely than Whites to have details held on the DNA database they are more easily detectable by police. However, the figures cannot simply be explained away by the argument that Black people are more likely to offend than other groups. Indeed the lifetime offending rate for Black males is in fact significantly lower than for White males.

Consecutive census findings initially by the Healthcare Commission and subsequently the Care Quality Commission reveal that Black people are similarly over-represented amongst admission rates into mental health care. The 2009 Census by the Care Quality Commission found that 22 per cent of all patients were from minority ethnic groups compared with 20 per cent for the 2005 Census. The rates of individuals subject to the Mental Health Act were higher than average for Black Caribbean, Black African, Other Black and White/Black Caribbean Mixed and Other White Groups.

### **Ways into mental health services**

And Black people are more likely than White people to take a particular route into mental health services – what has been termed 'an aversive pathway' by means of higher compulsory admission rates to hospital, greater involvement in legal and forensic settings and higher rates of transfer to medium and high security facilities.

*The lifetime offending rate for Black males is in fact significantly lower than for White males.*



## *An opportunity to advance policy lies within human rights legislation.*

Studies into criminal justice decision making have shown that professionals often more readily associate Black defendants with a sense of danger and this is reflected in the decisions they make. A study into the operation of the civil sections of the Mental Health Act 1983 too has found that police officers are prone to associating Black people with risk factors with the result that Black people are more likely to be detained by police under Section 136 of the MHA and taken to a 'place of safety' within the meaning of the Act – often a psychiatric hospital – thereby opening that channel into the psychiatric services.

In 2008 the Independent Police Complaints Commission carried out research which for the first time examined national data on the use of Section 136 by all 43 police forces in England and Wales. This showed that the rate of detention for Black people, when compared with the general population was almost twice as high as that for White people.

The rates of people from Other Black and Black Caribbean groups detained under Section 37/41 (where a person is sent to hospital for treatment via the courts under a restriction order) has remained higher than average for the last five years. Indeed, Black patients have been found to be almost twice as likely to be referred for treatment via the courts.

Prison, in particular, acts as a common point of referral to mental health services for Black people, with Black prisoners more likely than their White counterparts to be referred from prison establishments to psychiatric units.

Once within the mental health system the overwhelming evidence is that Black patients' experiences are more negative than those of White patients. Racism, cultural ignorance and stereotypical views can often combine with the stigma and anxiety associated with mental illness to undermine the ways in which services respond to Black communities, affecting decisions about treatment, medication and restriction. Figures show that Black patients are more likely to experience physical seclusion and restraint than other groups. A particularly high level of hands-on restraint of Black patients was revealed by the 2007 Count Me In census.

### **Ways of working**

Given the unequal treatment and over-representation that exists in both these areas, it is crucial that health, criminal justice and social care agencies explore and find ways of working with Black communities to address these problems. It is not enough, for example, to consult on initiatives after they have been decided upon, nor is it good enough to consult too narrowly.

Recent policy and guidance has not grasped the opportunity to fully address these issues. The conclusion of the Delivering Race Equality (DRE) initiative with mixed results appears to have left a vacuum which has not been filled by the New Horizons vision for 2020. It appears to be painted with too broad a brush to be meaningful to those groups with particular needs such as offenders and BME groups.

White Paper proposals to strip Primary

Care Trusts (PCTs) of their power to commission services and the handing of budgets to consortia of GPs – whilst at the same time cutting spending in real terms – may yet see traditionally 'unpopular' groups such as the mentally unwell and offenders pushed ever more to the margins.

The most significant piece of recent policy guidance on diversion, The Bradley Review, whilst setting out an unprecedented progressive direction of travel on issues concerning diversion, was fairly silent on issues affecting BME users. However, it did stipulate that diversion schemes should be considering the ways in which they can be meeting specificity of need for particular groups.

'Improving health, Supporting Justice', the National Delivery Plan of the Health and Social Care Programme Board which followed Bradley, did afford equalities issues more depth. This explored the need for robust impact assessments, stakeholder engagement and further exploration of a 'Count me in' census equivalent for the offender pathway and prisons in particular.

The National Delivery Plan set out the strategy for taking forward Lord Bradley's recommendations stating that it would 'address any adverse impact and improve access to services for disadvantaged groups'. This plan was subject to an equality impact assessment which provides some focus in that it discusses the way in which the seven equality strands are impacted by the strategy and accompanying policies.

The equality impact assessment makes clear that an opportunity to advance

policy lies within human rights legislation. A central purpose of the Human Rights Act 1998 is to institutionalise human rights thinking in public service provision. The opportunity surely exists to embed these principles into the delivery of healthcare services to offenders – including services to foreign nationals, a much neglected group within the criminal justice system.

## Foreign national offenders

Indeed, in the service user popularity stakes it is difficult to pinpoint who might come below foreign national offenders with mental health needs. Yet there is very real and unmet need here. Foreign national offenders often have mental health needs which go beyond, and are different from, those experienced by the general offender population (and indeed indigenous BME groups) and which can be exacerbated by other factors that render them more vulnerable than other offenders/defendants.

The available evidence points to negative experiences for foreign nationals in prison which can impact adversely on their mental health. Consecutive reports have found that the foreign national prisoner experience is extremely challenging and debilitating, whilst the trajectory for self-inflicted deaths amongst foreign national prisoners, which was generally declining from 2002 to 2005, has been rising since 2006.

The Chief Inspector of Prisons found that the experience of open-ended immigration detention had left many feeling depressed and considering self-harm or suicide. Her report provides several examples of inmates feeling seriously distressed or carrying out threats to harm themselves as a result of IND/UK Border Agency delays or an inability to obtain appropriate legal advice and

assistance while still being held in prison, and beyond the end of their sentences.

At the end of March 2009 there were 11,238 foreign national prisoners in British prisons (14 per cent of the overall prison population). One in five women in prison were of foreign nationality and over 50 per cent of female foreign national prisoners came from African and Caribbean BME groups. In addition to the usual health stressors that accompany being arrested and incarcerated, they may experience:

- mental health and welfare problems (such as isolation, separation from family, trauma and loss, particularly if they are seeking refuge or asylum)
- lack of access to information about their current experience
- lack of legal and immigration advice
- language barriers and a shortage of translation facilities
- a period of effectively being held in bureaucratic limbo following the serving of their sentence and prior to deportation
- limited preparation for release and insufficient access to resettlement programmes
- fear of return to their home country fuelled either by a lack of affinity with that country or for other reasons.

All these factors can impact on the experience of foreign nationals in the criminal justice process and, as such, affect their wellbeing and mental health.

The universal application of human rights principles demonstrates a key difference between these standards and other equalities laws in that the former applies to everyone. Individuals who break laws may compromise some of their rights and liberties (eg with regard to freedom of movement etc), but there remain human rights standards that must be adhered to no matter what the individual has done.

On this basis alone the equality impact assessment presents a template for better treatment and care of BME and foreign national offenders with mental health needs. The treatment and care which it advocates should be progressed in accordance with the key (FRED) principle of fairness, respect, equality and dignity.



Statistics produced annually under Section 95 of the Criminal Justice Act reveal the extent of the disproportionate involvement of BME people with criminal justice agencies as victims, suspects, defendants and prisoners.

- In 2008/09 there were over seven times more stop and searches of Black people per head of population than white people and over twice as many stop and searches per head of population of Asian people and people of Mixed ethnicity
- Of the Stop and Searches using Section 1 PACE and other legislation 15 per cent of searches carried out were of Black people, nine per cent were of Asian people, three per cent were of people of Mixed ethnicity and one per cent were of people from a Chinese or other background
- People of Mixed ethnicity were more likely than all other groups to be victims of crime: 35 per cent of people within this group were victims according to the British Crime Survey, 26 per cent of Asians were so affected while 24 per cent and 23 per cent of adults from Black and White backgrounds respectively were victims of crime
- In 2008/09 there were three times more arrests of Black people than of White people per 1,000 population
- As at June 2009 BME people accounted for 27 per cent of the overall prison population, including foreign nationals, compared with 25 per cent of the overall prison population in 2005. The Black group accounted for 14 per cent of the 27 per cent

The BME population is currently 15.8 per cent of the total population

Back in April I took part in a debate at the TUC Black Workers' Conference in Liverpool on mental health and BAME communities. I shared various information regarding the current trends and government thinking around race and mental health. However, what hit home and which shocked and angered delegates was the levels of over-representation of minority ethnic communities in the mental health services.



# Tackling mental health and racial inequalities in the Big Society

by Patrick Vernon, Chief Executive of the Afiya Trust

The latest 2009 Count Me In census paints a bleak and depressing story highlighting that the experience of Britain's BAME communities, particularly African and Caribbean, has not changed. Actually, if you take into account the impact of Community Treatment Orders matters are much worse.

The report also highlights how the Delivering Race Equality Programme (DRE) (similar in approach and with far-reaching

recommendations like the Macpherson report) has not made a significantly marked difference in reducing mental inequalities. There has been massive investment in mental health service provision, along with other programmes such as housing, employment/training and regeneration which contribute to tackling health inequalities. However, the lot of BAME communities around mental health inequalities has not changed in real terms

compared with the last 30 years.

In 1998 Paul Boateng was Under-Secretary of State at the Department of Health with responsibility for mental health. I remember him saying at a seminar to chief executives of mental health trusts, that 'heads would roll' if there was no marked difference in reversing the trend of black over-representation in the mental health system.

Unfortunately, heads have not rolled

## The reality is people don't take to the street to march about BAME mental health services.

> and the level of over-representation has increased. It is also a sad fact that unlike, say, gun and knife crime, deaths in custody, or hate crime, our treatment in mental health services and system failure does not attract the same level of community effort. The reality is people don't take to the street to march about BAME mental health services.

The lack of a strong community direction has an impact on how effectively groups can lobby and influence policy makers, commissioners and politicians. This issue has now created over three generations of BAME service users and carers whose lives and rights are denied and not respected. It must be taken seriously.

There are several reasons posited by academics and policy makers for mental health and health inequalities experienced by Britain's minority ethnic communities. These range from cultural behaviours (values, religion and belief systems) and impact of migration, to structural explanations such as social deprivation and exclusion.

Mainstream researchers and policy makers fail to acknowledge the growing evidence and 'real time' experiences of individuals and communities that racism, racist victimisation and discrimination can affect their health and wellbeing.

Every day racism and fear of racial discrimination and lack of information about services still does lead to people not accessing services when they need them most. It is this situation that needs changing if people from minority ethnic communities are to have fair and equitable access to health and social care.

Even the recent launch of the heralded Marmot Review on health inequalities has fallen into the same trap by not acknowledging the experience of historical racial inequalities and everyday racism which BAME communities experience as another dimension to this agenda.

In 2010 we all recognise that we have to be more sophisticated and even unpack the experiences and the meaning of BAME communities. This will give us greater understanding of the complexity of cultural identity, gender, age, religion, health status and sexuality, and their relationship with mental health inequalities.

However, as long as structural racism still exists in Britain today, race equality should not be swept under the carpet by academic researchers and policy makers, or left to certain sections of the media and the 'worried well' to say that multiculturalism has failed and all this stuff is pc nonsense!!

Despite all the rhetoric on equalities, diversity action plans and the importance

of a multicultural society there is still ignorance and denial from commissioners and service providers about our needs. Alongside this is the recognition that communities have their own resilience/survival strategies which can add value to service delivery. This ignorance leads to poor service delivery.

Eventually the argument goes that it is too difficult to work or engage with BAME communities, particularly service users and carers as they are either too sensitive or volatile to contribute on race equality issues and service improvement. This has been seen within the NHS, and to a lesser extent within local government.

The current approach in the NHS is one of world class commissioning using a third world mindset. We are still seen and treated as colonial subjects and not citizens. The former empire is now the new front line in deprived neighbourhoods and communities, especially where there is significant BAME population.

The Afiya Trust's focus has always been the relationship between mental health and the general wellbeing of BAME communities in the UK. We want to make sure New Horizons provides a landscape which is visibly different with transparent and evidential step change.

More importantly we want to see it make a connection with how mental health inequalities impact on the over-representation in services among a number of BAME communities and that there is real accountability and action. The recommendations in the Count Me In survey also miss the point about the nature of racism and discrimination in mental health services, and their impact on BAME communities in society.

The Afiya Trust's consultation on the Green Paper *Shaping the Future of Care Together*, which informed New Horizons, demonstrates that race equality needs to remain firmly on the agenda if future policy development is to work positively for black and minority ethnic communities.

A key task is to empower BAME communities to encourage dialogue and engagement with local and central governments, and public sector agencies. This has to be done through social marketing campaigns, good commissioning practices, rigorous and focused research, and developing new approaches to understanding diversity and community issues. We launched our manifesto in March this year with a clear vision and action plan for what a future government needs to tackle around race equality in the delivery of health and social care.

With the new government and its 'progressive politics agenda' we are still waiting for the finer details of their approach to race equality and mental health. However, one thing is quite clear. Discussion about the particular mental health inequalities faced by BAME communities has so far received limited, if any consideration in discussions around the new white paper on health.

This means we will all begin presenting and articulating to the government why the current mental health system has failed, along with developing solutions from our perspective on a range of issues. These include service user leadership, recovery and wellbeing, reviewing mental health legislation, funding and service development for BAME-led organisations, rooting out racist practice and calling to account mainstream services providers and commissioners.

I hope that the budget cuts in public expenditure will not target mainstream mental health services and the funding of BAME-led community-based organisations in a disproportionate and negative way that will increase mental health inequalities in a period of recession. Over the last several months, the 400 or so Community Development Workers who are part of DRE programme are being slowly being decommissioned by the back door by local commissioners and providers.

It is important that we defend and safeguard the gains that have been championed by service users, carers, health care professionals, academics and community organisations over the last 20 years. So we need to develop a campaign to prevent further cuts to these workers who play an important role as an interface between influencing and changing poor practice within mainstream service and acting as a conduit to the community and service users.

Finally, I hope that the Big Society vision of the government recognises that race equality still matters, and recognises the role BAME organisations can still play in supporting and delivering quality services.

For further details of The Afiya Trust manifesto go to [www.afiya-trust.org](http://www.afiya-trust.org)

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Race on the Agenda

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