

# **Response to the New Horizons Consultation Based on the Consultation Events Organised by the Afiya Trust**

## **1. Introduction**

The Afiya Trust is a national black and minority ethnic (BME) led organisation working to reduce health inequalities faced by racialised communities. We host several networks that bring together service users, carers, professionals, academics and community members who are concerned about mental health service delivery and care provision and want to see changes. Our mental health work sits amidst other work in cancer, stroke and other health issues and in promoting the well-being of England's diverse and large ethnic minority populations.

The Afiya Trust welcomes the opportunity to respond to the *New Horizons: Towards a Shared Vision for Mental Health* (NH) consultation. We welcome the vision and life-cycle approach of the strategy and the fact that the document positions mental health within the work towards addressing the inequalities in society, with a focus on well being and prevention.

The NH document states that, by 2020, "inequalities for black and minority ethnic groups in access to and experience of mental health care will have disappeared" (p. 5). As an organisation invested in reducing inequalities in health for racialised communities, we see this as a welcome commitment on the part of the government and will hold the government to account.

Afiya also welcomes the broader human rights and equalities perspectives that underpin the NH document. The focus on tackling stigma and promoting social inclusion sits well within this perspective. The document also stresses the importance of cross-departmental and partnership working, which is also encouraging.

Clearly the NH document and strategy has the potential to bring about some much needed change in mental health service delivery and promotion of mental well being. While the Afiya Trust and the individuals and representatives of organisations who took part in the consultations we organised welcome the broader vision and values of the NH document, we have several concerns about both the process and the content of the document. These are discussed below.

## **2. The Consultation Process**

The Afiya Trust organised three consultation events – on 23<sup>rd</sup> September in London, 30<sup>th</sup> September in Liverpool and 1<sup>st</sup> October in Birmingham. The events were organised in partnership with and with financial help and support from the National Survivor User Network, the Department of Health, Liverpool PCT, North West Strategic Health Authority, Heal 8 and Birmingham Midland Hearts. Around 200 people in total attended the three events.

In addition to the regional events, we organised web-based consultation, using a questionnaire developed with NH consultation questions, along with some other questions looking at the future priorities in mental health work for BME communities and Afiya in particular. We received 58 responses to this.

### **3. Responses to the NH document**

#### **1. Involvement of BME organisations in the development of mental health strategy**

We understand that there has been an informal consultation process between the Department of Health and The Future Vision Coalition over the last eighteen months. The Coalition represents all the mainstream mental health charities along with the Royal College of Psychiatrists, NHS Confederation and the ADASS. It is clear that the "Future Vision" document has heavily influenced the NH document and carries the same problems that will be discussed later.

The Future Vision Coalition is marked by the absence of an organisation representing BME communities. Afiya is concerned that there has been no pre-release dialogue with BME communities or with organisations working nationally or locally with BME communities. There has been no contact during the development of NH with Afiya or with any other national or regional BME organisations.

This lack of dialogue is clearly evident in the development of a strategy that does not focus on the very definite and much-evidenced needs of BME communities in this country. **We demand that a lead BME organisation with extensive links with England's minority ethnic communities is involved centrally in the revisions to the NH document and future development of the strategy and action plan.**

#### **2. The timing of the consultation**

NH was launched by the government on the 23<sup>rd</sup> July with the final submission date fixed on the 15<sup>th</sup> of October. We question how serious the government was in consulting with BME communities and professional stakeholders on such a vital and important area of policy development as the consultation period was insufficient and the timing inappropriate as it coincided with general school holidays, Ramadan and Eid. Despite our extensive link with communities and organisations, we found it a challenge to organise meaningful consultations with all stakeholders in the regions.

We understand that the insufficiency of consultation period has been raised by other BME groups (for example, the BME Alliance East Midlands). Like these groups, we also find that the lack of engagement with BME groups prior to release and the timing has resulted in less than sufficient awareness of the document among BME groups. More startling was the lack of awareness of the NH document among community development workers.

#### **3. Use of research and evidence**

The Equality Impact Assessment for the NH document, we believe, was based on a selective and limited literature review and did not engage with stakeholders to develop a robust impact assessment. The literature used in the impact assessment and in the NH document makes little reference to the work of BME academics, professionals and service users who have contributed to developing a clear body of evidence over the last 30 years.

The focus on "population" mental health has, we believe, taken away the need for a strategy based on the very real and different needs of minority ethnic communities in this country. Responses from our consultations showed that the NH strategy has not adequately dealt with the abundantly clear evidence (for

example the continuing inequalities in mental health service delivery recorded in *Count Me In* since 2005) showing the continuing need to focus on the specific needs of communities. **The choice of focus and decisions about investment must be made based on a rigorous mapping of existing evidence and not on changing political fashions.**

#### **4. Definition of mental well-being**

NH defines mental well-being as our ability to cope with life's problems and make the most of opportunities. This definition needs to be developed further to include the specific life circumstances of diverse communities. For example, mental well-being for BME communities is dependent on experiences of racism, feelings of belonging or disinheritance, social exclusion, and so on. It is a term loaded by cultural references. Consequently, any strategy that aims to promote mental well-being needs a diversity of approaches.

The workshops at the consultation events on mental health and different approaches explored issues around complementary and culturally specific therapies including Islamic and African centred approaches. We are concerned that the strategy to promote mental well-being does not discuss the extreme importance of cultural sensitivity. **The figure on p.13 showing a framework for developing mental well-being needs at its heart a commitment to equality of opportunities and diversity of approaches.**

#### **5. Race Equality Still Matters**

The NH document states that the programme of action will advance two main aims: 1) improving the mental health and well-being of the population; and 2) improving the quality and accessibility of services for people with poor mental health. This broader vision is valid and necessary. However, what the strategy document has not discussed is how the continuing specific needs of minority ethnic communities will be addressed.

Over the last four years, the Delivering Race Equality (DRE) programme has kept the focus on racial inequalities alive, although opinion differs on how effective it has been in tackling these inequalities. We are concerned that the NH document does not reference the DRE programme adequately, nor does it make clear how the work of the DRE will be carried forward.

Even with the existence of a programme like DRE, the inequalities faced by minority ethnic communities within mental health services continue. This was clearly evidenced by the 2008 *Count Me In* census. The NH document does not, despite its stated intent to reduce inequalities for BME communities, make clear the government's strategies for achieving and delivering equitable services. The document, we feel, takes on a "colour-blind" approach, making a huge shift from the focus on race and culture in the last few years into a "one size fits all" approach on well-being and mental health.

Our consultations showed that there is a great deal of concern that the broader population approach would result in diverting attention from communities whose needs are not met to areas where it might be easier to make changes. As one respondent put it:

"Without improving BME community health, it will be hard to really improve population health and well-being. Someone needs to make sure that overall

statistics aren't improved in just one area, say white middle class, so that makes it look like progress has been made, while others get left behind."

With the end of the DRE programme and with the focus shifting to a broader equalities agenda, there is real fear among BME communities that race inequalities will become invisible and the specific needs of minority ethnic communities will go unmet. **We would like to see an action plan that sets out clearly how the strategy will achieve its stated aim of eradicating the inequalities faced by BME groups in access to and experience of mental health care.**

## **6. Clarify how the value of justice and human rights sits alongside the Mental Health Act**

On paper, the guiding values of the NH document look fundamental to any service delivery policy. However, a large part of mental health care and service delivery is governed by the Mental Health Act, which contravenes, in many aspects, the idea of human rights. Detention, coercion and restrictions to liberty – tenets fundamental to the idea of human rights – are, rightly or wrongly, aspects of mental health service delivery, reinforced by the law. Unlike the Scottish law, the MHA does not contain an element of non-discrimination.

While the document talks about social inclusion as a human right, it does not explain how human rights will be protected when the MHA comes into action in the care of an individual. **There needs to be a clear articulation of how the human rights of people who access the mental health system will be protected.**

## **7. Tackling stigma and discrimination**

People from minority ethnic communities face the stigma of mental health in a much more complex and fundamental manner, as it is combined with the negative stereotypes based on racism, islamophobia and cultural ignorance. The "big, black, dangerous" stereotype, commented on by the inquiry into the death of Orville Blackwood and others in 1993, continue to be pervasive in the media.

Two anti-stigma and discrimination programmes have been in place recently – Shift, funded by the DH, and Time to Change, funded by the Big Lottery and Comic Relief. While Shift has done some work with BME communities, neither of the programmes have addressed the complex and pervasive nature of the stigma and discrimination faced by minority ethnic communities, despite several million pounds investment.

The stigma and media panels at the Afiya consultations presented an overwhelming number of examples of negative media and societal stereotyping of race and mental health. The over-representation of some communities at the acute end of the mental health system combined with racist and negative views of those communities produce and perpetuate a situation that needs focused work with the media and with communities. Many of the ambitions laid out in the NH document – mental well-being, recovery, resilience, social inclusion and justice – can be achieved only if there is sustained work and investment in this area. **Given the failure of the existing programmes to address this complex situation, we would like to see a clear focus in the strategy to address the multiple stigma and discrimination faced by BME communities.**

## 8. Criminal justice system

We feel that a major omission in NH is the relationship between the criminal justice system and the pathways into care for some BME communities, especially men and women from African-Caribbean communities. The number of people from BME communities within the criminal justice system is disproportionate to their numbers in communities. The experience of BME communities is marked by:

- Criminal justice system ending up as a gateway to mental health services
- Negative prison experiences and the impact on mental well-being
- Poorer access to staff and services
- Poorer access to and the stigma attached to accessing resettlement and diversion schemes
- Poorer experiences of refugee, asylum seeker and foreign national communities, especially with added impact of language issues, social isolation, trauma and discrimination

There is a need to map the existing evidence that shows decreasing investment in schemes that benefit BME communities. If mental well-being is to be a meaningful reality for people from BME communities, there is a need to tackle head on the relationship between the criminal justice system and mental health services. **NH strategy requires a clear focus on criminal justice and its links with mental health, with an action plan laying out how commissioning, investment, service delivery and monitoring will take place.**

## 9. Advocacy

Another key omission in NH is a focus on advocacy. The document talks about the personalisation agenda and about recovery. While, theoretically, everyone has the choice, control and power to access personalised services, in reality access is determined by several factors like language, whether one is detained under the MHA, being at the acute end of the spectrum, or simply lacking the awareness or knowledge of what is available. The consultation workshops on personalisation highlighted the fact that the values of choice and control in personalisation will become a reality for BME communities only if they have access to good independent, culturally appropriate advocacy services.

Access to culturally appropriate advocacy is important in the context of the amendments to the Mental Health Act and the Mental Capacity Act as well. Advocacy is important in raising awareness and educating BME communities of mental health issues and procedures so that access to appropriate care services become universal.

**Given this key role, it is imperative that any future strategy for mental health should focus on the need for culturally appropriate advocacy and strategies for sustainable investment in this area.**

## 10. The role of service users and carers

Given the emphasis on choice, control and person-centred approach in NH, there needs to be a more pronounced explication of user and carer involvement in the strategy. The policy of user/carers involvement over the last few years had made a huge amount of difference in some areas of service delivery, while in others it has remained tokenistic. It is imperative that the future strategy focuses on meaningful user involvement.

**What we would like to see is an extension of user involvement into placing a mandatory duty on services to be evaluated and monitored by those who use those services.**

## **11. Partnership working and investment**

NH places a welcome emphasis on partnership working. However, as discussed earlier, there has been an omission in enabling meaningful partnerships with BME communities and organisations even in the development of this document. **This is a serious omission and needs to be rectified before the strategy is developed any further.**

What is also unclear from the document is how resources will be invested equitably. World class commissioning has the right references around needs assessment of local populations but this is often not reflected in the final commissioning of contracts. Current mode of block contracts works against BME community organisations who do not have the resources to compete with large mainstream charities and the private sector. The emerging evidence in how IMHA and IMCA services are commissioned is a good example of this.

Across the board, investment in smaller, local community based BME organisations, delivering specific services based on local needs, is decreasing. This is likely to get worse given the current financial climate. The strategy, while setting high aspirations, is thin on how these aspirations will be achieved and how investment will be made. **A clear strategy for appropriate and proportionate allocation of resources to organisations and services that understand and work with local communities is absolutely essential.**

## **12. Getting there**

We feel that the NH document does not dwell enough on how the aspirations laid out in the document will be achieved. The document states some key elements in achieving its two main aims of improving mental health and well-being of the population and in improving the quality and accessibility of services for people with poor mental health (p.98).

- A clear strategy supported by a broad consensus

**There is a lack of engagement with BME communities in the development of this document. In order to achieve a broad consensus to the strategy, BME organisations with links to various communities nationally need to be centrally involved.**

- Prioritisation of mental health nationally and locally across government and all sectors

**Key partnerships need to be developed with clear plan for cross-sectoral working and investment, especially with criminal justice, education, employment, media, housing and so on.**

- Local and national leadership

**The expertise of what is needed and how to achieve it is within communities and among those who use services. What is lacking is investment. Key links need to be made with community organisations and service user and carer groups from a variety of backgrounds.**

- Evidence-based service models and approaches

**The document has not represented adequately the existing research evidence on the needs of BME communities and the knowledge base developed over the last decades. A clearer mapping of evidence, looking at the specific needs of communities, should form the basis of strategy development and action planning.**

- Effective and resourced commissioning, both multi-agency and specialist

**The commissioning process needs to be clearer on how investment will be made equitably. Smaller local organisations, with better understanding of the needs of communities, should be supported to bid for contracts and deliver services. Developing partnerships with BME organisations locally should be made mandatory for large mainstream charities and the private sector bidding for block contracts.**

- Information, monitoring and regulation and high-quality outcome measures

**Service users and carers should have a crucial role in monitoring outcomes and procedures. This should be supported by policy and guidance, and be effectively resourced.**

- A skilled workforce

**A skilled workforce is one that can work effectively with people from a diverse range of cultures and belief systems. Training should be one element, but equally important is the development of a workforce that represents the cultural and linguistic diversity of local communities.**

### **13. Additions to the strategy**

We would like to see the following additions to the strategy:

- Clear targets in the action plan in realising the ambitions laid out in the strategy
- Clear structure for accountability in realising targets, partnership and leadership building
- Link the 2020 target for reducing inequalities to performance targets for CEOs of MHTs and PCTs
- Regular mandatory reports on outcomes to service user organisations, BME mental health forums at local, regional and national levels
- Commitment for dedicated funding for BME organisations to tackle stigma
- An advisory group at the national level to ensure focus on equality and diversity elements from BME perspectives in further development of the New Horizons document and action plan

### **Conclusion**

We welcome this opportunity to respond to the consultation. Our focus has always been on the mental health and well-being of BME communities in the UK. We want to make sure that New Horizons provides a landscape that is visibly different with transparent and evidential step change. More importantly, we want to see it make a connection with how inequalities in mental health services impact on the lives of people from BME communities.

We look forward to working with the Department of Health in creating a robust strategy and action plan that will make a real difference to the mental health of BME communities.

## **Appendix**

### **List of organisations represented at the consultations**

ACCI  
African and Caribbean Mental Health Services  
African Caribbean MH Services  
Alzheimers Society  
An-Nisa Society  
Arts and Minds  
Ashram Housing Association  
Barnet, Enfield and Haringey Mental Health Trust  
Bedfordshire and Luton Partnership Mental Health and Social Care Trust  
Birmingham and Solihull Mental Health Foundation Trust  
Birmingham and Solihull Mental Health Trust  
Birmingham City Council  
Birmingham East and North  
Birmingham Mind  
Blackspine  
BME Alliance East Midlands  
Bolton Patients Council for Mental Health  
CDW PCT Wolverhampton  
Ceridian UK  
City and Hackney PCT  
CNWL NHS Foundation Trust  
Coaching Cultures  
Commissioning Support for London  
Community Support Network  
Coventry and Warwickshire PCT  
Dare to Care  
Diverse Minds  
East London Foundation Trust  
Equalities National Council  
Friends, Families and Travellers  
Friendship Care and Housing  
Future Health and Social Care  
Getting 2gether (G2G)  
Hampshire County Council Adult Services  
Hampshire Partnership NHS Foundation Trust  
Heal 8  
Health Exchange/Equality Plus  
Independent Living Alliance  
Independent Newham Users' Forum  
Irish Community Care  
Joint Forum  
Kuumba Foundation  
Lancashire Advocacy  
Life Changer Empowering Ministry

Liverpool Advocacy Project  
Liverpool City Council  
Liverpool Housing Trust  
Liverpool PCT  
Liverpool Somali Healthy Mind  
Liverpool University  
Mary Seacole House  
Mental health accomodation care and support services  
Mental Health Helplines Partnership  
Mental Health Providers Forum  
Mersey Care NHS Trust  
Middlesex University  
Midland Heart Birmingham  
Migrant Refugee Communities Forum  
Milton Keynes Service User Recovery Forum  
My Time  
NACRO  
Netherton Health Centre  
NHS BEN  
NHS Islington  
North Liverpool PBC consortium  
North Liverpool PBC Consortium  
Nottinghamshire Healthcare NHS Trust  
Nottinghamshire Heatlhcare NHS Trust  
Notts Healthcare NHS Trust  
One Aim  
Oxfordshire Mental Health Matters  
Pattigift  
Penrose  
Perry Barr Job Centre Plus  
RDC West Midlands  
Rethink  
Rethink African Caribbean Carers/Elderly Service  
Richmond Borough MIND  
Richmond Fellowship  
Rochdale and District Mind  
Royal Edinburgh Hospital (Minority Ethnic Health Service)  
Royal Holloway University London  
Sahelia House  
Sanctuary Community Voice  
Sheffield User Survivor Trainers  
SIMBA (Share in Maudsley Black Action)  
Social Action for Health  
Sola Arts  
South Bank University  
South London and Maudsley NHS Foundation Trust  
South Staffords & Shropshire NHS Health Foundation Trust  
South West Development Centre

Southside Partnership / Fanon Centre  
Southwark Mind  
Suffolk Employment Care  
Suffolk Mental Health Partnerships  
Tamarind  
The Advocacy Project  
The Afiya Trust  
Tower Hamlet African Caribbean Mental Health Organisation  
UKAN  
User Voice Birmingham  
Users in Partnership Birmingham  
Voluntary Action Camden  
Walsall Community Health  
Walsall PCT  
Wavertree  
Whitechapel Centre  
Worcestershire Mental Health Partnership NHS Trust