Achieving Equality in Health and Social Care

A framework for action

The Afiya Trust

Foreword

THE AFIYA TRUST is a national second tier organisation with an England-wide remit to reduce inequality in health and social care provision for racialised communities. We host several networks that bring together service users, carers, professionals, academics and community members who are concerned about health and social care provision and want to see positive changes. Over the years our work has focused on mental health, cancer, stroke and other health issues, on service user and carer concerns, and on promoting the wellbeing of England's diverse communities. We host the National Black Carers and Carers Workers Network, the National BME Mental Health Network, Catch-a-Fiya Mental Health Service User and Carer Network, and the National BME Mental Health Advocacy Network. Through our networks we have access to around 1000 individuals and organisations, and their views and opinions inform our work and policy.

ACKNOWLEDGEMENTS

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cover picture/posed by models.

The Afiya Trust is launching "Achieving Equality in Health and Social Care: A Framework for Action" to start a process of bringing people and communities together to make the government and key agencies more accountable in tackling the persistent race inequalities in health and social care. It has been over 60 years since the Windrush docked on these shores. Since then people from the former Commonwealth, the European Union and conflict zones around the world have made the UK their home. They have formed productive communities and have added to the nation's resources. However, these communities still need to articulate their needs for equitable services and work against the health inequalities which prevent them from enjoying a full and active life. We still need to influence the government's thinking that race continues to matter. To do this and to develop quality health and social care services,

we need the active support of the general public, the media, councillors, MPs and MEPs.

Unfortunately, over the last decade, with public sector cutbacks and the retreat of the voluntary sector, a lot of specialist community-based services addressing the needs of specific communities have disappeared. As a result the future looks even bleaker.

We hope that our manifesto in the form of a framework for action will have the potential to empower local communities and encourage greater discussion and engagement with the local and central governments and public sector agencies.

The Afiya Trust's priority, as an organisation, is to build our infrastructure so that we can play an effective leadership role in reporting and advocating on behalf of the diverse communities we work with nationally and in developing an inclusive approach to public health. We hope that the next government will work in partnership with communities and organisations to take forward our recommendations, and show their commitment to eradicating racism and reducing the health inequalities that racialised communities continue to face.

Patrick Vernon
CEO, The Afiya Trust

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Our call to action is based on a seven-point action plan:

1. **ADDRESS** the diversity of identities and experiences within communities while delivering health and social care services

2. **DEVELOP** systems to enable racialised communities to influence policy making at the top level

3. **SUPPORT** community-led social marketing campaigns to challenge inequalities and raise awareness

4. **SET** mandatory duty for accountability and outcomes on health equality

5. **MONITOR** the commissioning process for effectiveness in meeting community needs

6. **ENSURE** service user and carer leadership in evaluation of services

7. **RECOGNISE** and respect cultural heritage, identity and belief systems of communities

" [Wellbeing is] having hope, choice, opportunity and control, with meaning and purpose of self and community. "
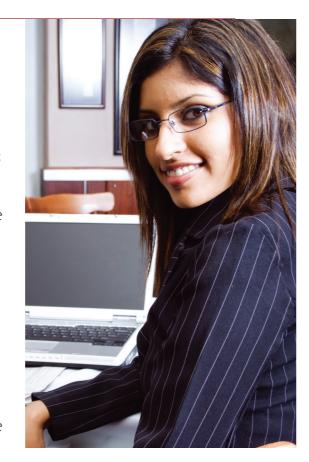
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introduction

minority ethnic communities in the UK

A MULTI-CULTURAL, multi-faith and multi-lingual society is one of the great advantages of the UK in the 21st century. This rich diversity is an asset for any government coming into power at a time when the recent financial crisis is continuing to test the resources and resilience of the nation. Looking after the health and wellbeing of this diverse population is one of the important tasks that the new government has to focus on. Increasingly, it is clear that the diverse and different communities in the UK have not had equal access to

health and social care services and that a universal model of service delivery is not meeting the specific needs of these communities.

It is time, therefore, that the government, policymakers, commissioners and service providers take a renewed look at the needs of different communities and work with the extensive expertise and knowledge on the ground within these communities, the voluntary sector and community-based organisations. This document aims to influence that process.

How this document was produced

The conclusions here are based on extensive consultations with health and social care service users and their families, community groups, organisations working with racialised[1] communities, and other expert and interested parties. The consultations focused on a range of themes including the government's new mental health strategy document New Horizons (DH 2009a), the green paper Shaping the Future of Care Together (DH 2009b), and the development of a national black and minority ethnic mental health advocacy network. The consulta-

tions, which took the form of regional workshops and online surveys, generated around 500 responses.

The document also incorporates insights from research and ongoing work through our networks, including the National BME Mental Health Network, Catch-a-Fiya National BME Mental Health Service User Carer Network, the Mental Health Advocacy Network and the National Black Carers and Carers Workers Network. In this sense, it reflects the current concerns of racialised communities in the context of the evidence

base on health and social care.

Finally, we have worked in partnership with a number of race equality organisations in developing a Racial Justice Manifesto which highlights the economic, social and political contributions which racialised communities have contributed to Britain, along and with a future vision for racial justice. This manifesto is led by Equanomics, The 1990 Trust, Operation Black Vote, JUST West Yorkshire, and many other organisations including The Afiya Trust.

[1] The Afiya Trust prefers to use the term "racialised communities" to refer to communities in the UK who are categorised or differentiated on the basis of their race, ethnicity, religion, nationality and culture. We use this term interchangeably with "minority ethnic communities."

THE TERM "black and minority ethnic (BME) communities," is often used to refer to communities minoritised and racialised in relation to the national population. Despite its unifying tones it embraces a vibrant diversity in terms of race, ethnicity, religion, skin colour, nationality, identity and culture. The 2001 census showed that there were 4.6 million (7.9% of the total population) people from minority ethnic backgrounds living in the UK. Experimental statistics for 2007 show that minority ethnic communities constitute 16.3% of the total population in England[2]. The 2001 census also recognised that the growing number of people from a mixed heritage background is significant in the population by officially categorising them as a new group. The 2001 census does not give us population estimates of newer migrant communities (e.g., people from the eight Eastern European countries which recently joined the EU).

The Office of National Statistics' 2004 data[3] shows that 88% of people from Mixed ethnic, 86% from Black Caribbean, 83% Pakistani, 83% Other Black, 82% Bangladeshi and 75% Indian groups identified themselves as British, English, Scottish or Welsh, with the majority identifying themselves as British.

Diversity, difference and shared experiences

It is important to remember that these headline statistics hide a "super-diversity," (Fanshawe and Sriskandarajah 2010) and includes communities that are diverse in themselves and people with multiple and fluid identities. For example, it is common to talk about "South Asian culture," but the South Asian communities in the UK include people with different nationalities, religions, cultures, belief systems, languages and food habits, migration histories and experiences of socio-cultural life in the UK. Their socio-economic or health experiences are not uniform. To give just one example, the unemployment rate for Pakistani women in 2004 was 20% while for Indian men it was 7%[4].

While the minority ethnic communities in the UK are extremely diverse, they also share a similarity of experiences. For example, communities from post-colonial countries share a past that is vitally marked by slavery and colonialism. Their experiences as migrant communities in the UK were defined

by these histories, the effects of which are still apparent in the lives of their third generation British descendants. While other minority communities like those from Eastern European countries may not share this history, their experiences of racism and discrimination find common ground in its root causes of fear, stereotypes and the process of "othering" (marking a group as different by a process of exclusion).

The diverse experiences and needs of the UK's minority ethnic population are also defined by other markers of identity such as age, faith, gender, sexuality, disability, marital status, education and socio-economic status. The experience of discrimination, for many people, is at multiple and cross-cutting levels. A focus on "BME" health and social care should not miss out on the specific needs of people based on their specific circumstances.

We believe that the particular needs of individuals from specific communities can only be addressed from within structures and systems that pay attention both to the diversity/difference between and within communities and to their shared common experiences.

> **Race equality has many dimensions. Take for example a black, disabled, female single parent – she will face discrimination on all these levels… All BME people are not able-bodied males!**

[2] http://www.neighbourhood.statistics.gov.uk [Accessed 24 February 2010]
[3] http://www.statistics.gov.uk/cci/nugget.asp?id=459 [Accessed 24 February 2010]
[4] http://www.statistics.gov.uk/cci/nugget.asp?id=462 [Accessed 24 February 2010]

health inequalities

what needs to change

> Getting it right for BME communities in all their diversity means getting it right for everyone. "

RESEARCH in health and social care shows that many minority ethnic communities experience poorer health in comparison to the national population. Research also shows that there is great disparity in how they access health and social care services. The extent of health and social care inequalities varies from community to community and shows the need for focused support and work with each community.

It is not possible to examine all available data regarding the various communities and health conditions in this document. The following is a quick snapshot of health disparities, access and experiences of health and social care services and other issues faced by minority ethnic communities.

Disparity in health outcomes

- Self-reported health problems like anxiety, respiratory problems like asthma and bronchitis and chest pain were twice to five times more prevalent among Gypsy Traveller communities (Parry et al 2004)

- There is evidence of significant levels of ill-health due to trauma, isolation, immunity related problems, sexual health, disability and undiagnosed issues among refugee and asylum seeker groups (Patel and Kelly 2006)

- The infant mortality rate in England and Wales for children born to mothers from Pakistan is double the average (Race for Health nd)

- The risk of cardiovascular and renal complications is greater in patients from South Asian backgrounds, with 50% higher mortality rate (DH 2008a)

- People from minority ethnic communities are up to six times more likely to develop diabetes (APG and Diabetes UK 2006)

- People of African and Caribbean origin are at increased risk of having a stroke, and the number of people affected by the condition is higher among this ethnic group than any other[5]

- South Asians have a higher incidence of liver cancer when compared to the general population. South Asian women have a higher risk of oral cancer. Black men and women have a higher risk of cancers of the stomach and liver, and black men have a higher risk of prostate cancer and are more likely to die younger from this (NCIN 2009)

- There is a high incidence of dementia and depression among minority ethnic women over the age of 65 (Shah 2008)

- Young people from BME groups show disproportionate experience of many of the known risk factors for developing mental health problems, including exclusion from school, being in care, involvement with the criminal justice system and homelessness (Kurtz and Street 2006)

- The UKOSS survey (2009) showed that Severe Maternal Morbidity was more than twice as common among women of African (2.35 RR) and Caribbean (2.45 RR) origin (Knight et al, 2009)

Disparity within health and social care services

- Rates of detention under the Mental Health Act are higher than average for Black Caribbean, Black African, Other Black, Mixed, Other White and Pakistani groups. Rates of referral through GPs were lower than average and through the criminal justice system higher than average for some ethnic minority groups (Care Quality Commission 2010)

- Rates of supervised community treatment orders were higher than average for Indian, Bangladeshi, Black Caribbean and Other Black groups by 43% to 87%

- (Care Quality Commission 2010)

- Men from Bangladeshi, Black Caribbean and Irish groups were more likely to smoke than their counterparts in the general population[6], but less likely to receive smoking cessation interventions (Stewart et al 2002)

- Ethnic inequality exists in the reported use of screening for cervical cancer (Moser et al 2009), although South Asian and Black women above the age of 65 have a higher incidence of cervical cancer (NCIN 2009)

- Asylum seeker groups have difficulties in obtaining health care, registering with GPs and accessing health checks, screening or immunisation (Burnett & Peel 2001a, 2001b), and poorer health persists in those granted full refugee status

- Irish (2.5%), Bangladeshi (2.4%) and Pakistani (2.4%) groups had the highest rates of spending 50 hours a week or more caring according to the 2001 census figures[7], but many minority ethnic carers tend to care unaided and in isolation (Seabrooke and Milne, 2004, NBCCWN 2008)

respiratory problems like asthma and bronchitis and chest pain were twice to five times more prevalent among Gypsy Traveller communities

South Asian and Black women above the age of 65 have a higher incidence of cervical cancer

[5]http://www.nhs.uk/Conditions/Stroke/Pages/Introduction.aspx [Accessed 1 March 2010]

[6]http://www.statistics.gov.uk/cci/nugget.asp?id=466 [Accessed 24 February 2010]
[7]http://www.statistics.gov.uk/cci/nugget.asp?id=465 [Accessed 24 February 2010]

" Particular BME communities continue to be marginalised, despite being lead stakeholders in initiatives for race equality, and the trend of marginalisation continues through a smokescreen of poor and partially implemented race equality schemes. **"**

Disparity in awareness of and influence over health and social care services

- Many minority ethnic communities have poor access to health and social care services for a variety of reasons including language barriers, lack of awareness/ information, social isolation, lack of culturally sensitive services and negative attitudes about communities

- Over 80% of Turkish/ Kurdish and Cypriot/Turkish men in East London said they did not know of existing mental health services and treatments in their area (Tas et al 2008)

- Sight loss services are poorly prepared to meet the needs of people with visual impairments from minority ethnic groups, while community organisations in these groups do not know what services might be available to their members (Joule & Levenson 2009)

- People with learning disabilities from BME communities are one of the social groups who are "least often heard and most often excluded" (DH 2009c)

- Carers from minority ethnic communities are rarely the focus of social work assessment and support (NBCCWN 2008)

- Service users from minority ethnic communities are dissatisfied with the opportunities, modes and levels of influence they had in user involvement activities (Kalathil 2009, Belgum 2006)

" In order for BME communities to have a real stake in service provision around health and social care there must be recognition that we hold most of the answers to providing quality care to our communities. **"**

Racism and health inequalities

THERE ARE SEVERAL reasons for the continuing health inequalities experienced by racialised communities in the UK. These include individual/ community factors including cultural behaviours and structural explanations such as social deprivation and exclusion (Nazroo 2001). Equally compelling is the evidence that racism and racist victimisation and discrimination can affect a person's and community's health (Karlsen 2007, Nazroo 2003).

A key finding from various research studies and from service user and carers feedback is the impact of everyday and structural racism – both as a causal factor for social deprivation and distress leading to ill-health, and as a barrier in accessing services (Williams and Johnson 2010). Unfortunately, this is not often reflected in government policy development. This is a gap in the recently published Marmot Review (2010) of health inequalities, although the review does acknowledge that "other inequalities intersect in important and complex ways with socioeconomic position in shaping people's health status" (p 88-89).

The acknowledgement of the existence of institutional racism,

" The key is identifying the knowledge and power that service users have. Work with them and provide the services that they need; not what you think they need. **"**

following the David Bennett Inquiry (NSCSHA 2003), marked a turning point in the provision of mental health services to minority ethnic communities and led to the development of the Delivering Race Equality Programme (DH 2005). The report summarising the programme (Wilson 2009) after five years of work and investment, however, makes no mention of institutional racism or how it has been tackled. It is not incidental that, despite a dedicated programme and a massive investment in mental health service provision, the Count Me In 2009 census (Care Quality Commission 2010) has not found any substantive change

in the experiences of some minority ethnic communities within mental health services.

During 2008-2009, the National Black Carers and Carers Workers Network's regional conferences flagged up the fact that some local authorities and primary care trusts had no knowledge of or contact with minority ethnic communities in their areas. Ignorance about communities and their needs can lead to poor service delivery. Fear of racial discrimination and a lack of information about services can lead people to not access services when they need them most.

The key message that emerged from our consultations is that race equality still matters and should be at the centre of all future policy development in health and social care. While there is an acknowledgement that service users, carers and communities should be at the centre of policy development, the opportunities for participation or leadership for people from racialised communities have remained minimal (NBCCWN 2008, Kalathil 2009). This situation needs changing if people from racialised communities are to have equal and equitable access to health and social care.

THE AFIYA TRUST

our vision ——————————————————— a framework for action

THE WORD "AFIYA," which in Swahili and Arabic languages means wellbeing, is reflective of our belief in systems and interventions beyond the western medical models in promoting good health. Our vision of a healthy community is one where a person's health is not dependent on his/her race, ethnicity, cultural origins or identity; one where no single person or group is discriminated against in the process of accessing the care they need because of the social group to which they belong; one where there is equality of access to the resources that support our sense of wellbeing. Further, it is one where the health of an individual is seen as contributing to the health of all.

Wellbeing, we believe, is not just an absence of ill-health. It is a subjectively defined, culturally loaded term. We see working towards wellbeing as encompassing a person's individual or collective identity and their sense of self, and

rooted in equality and social justice.

Our vision of an appropriate and effective health and social care service is one with the needs of service users, carers and communities at its heart, one that is developed and delivered in partnership with them and one that is accountable to them through rigorous and transparent processes.

We believe the government can support the wellbeing of individuals and communities by:

- Eradicating the continuing existence of racial inequalities and their adverse impact on people's health and wellbeing

- Making health a matter of social justice

- Empowering and resourcing local communities to define and effect change

Achieving health equality

Our framework for action is based on a seven-pronged approach:

1 Address the diversity of identities and experiences within communities while delivering services

Health and social care services need to be tailored in a more nuanced and detailed way rather than setting general targets to reach "BME" communities. A Vietnamese non-English speaking service user may not find a generic "BME" service useful. Service delivery should be based on a rigorous needs analysis of local communities. Cross-borough multi-agency commissioning should be made part of service development policies to meet the needs of smaller groups in any given area. Positive action, as recommended by the Equalities and Human Rights Commission and entrenched in law (EHRC

2009), should be used to create a more diverse workforce with the skills to work in flexible, person-centred ways.

2 Develop systems to enable racialised communities to nfluence policy making at the top level

There is work yet to be done to make the new policy and legal developments, like the Single Equalities Bill, the New Horizons strategy and the green paper on the future of care, relevant and effective for racialised communities. We believe that this work needs to be influenced by proper community participation. The government should set up an advisory group with the power to influence decision making at the top

level. This advisory group should focus on equality and diversity elements from different community perspectives in developing health and social care and should report directly to the Secretary of State for Health and the Chief Medical Officer. The advisory group should include service users, carers and people working directly with local communities and be representative of the diversity within communities.

3 Support community-led social marketing campaigns to challenge inequalities and raise awareness

There is lack of information about health and social care provision and about certain health conditions within

communities. There is stigma about particular health conditions and accessing services within communities. This is, in many cases, exacerbated by multiple levels of discrimination in the wider society and the media. Proper investment needs to be made to raise awareness within communities. Communities need to know more about their rights and how to ensure they are supported as required by various legislative measures. Social marketing is a powerful tool to challenge the "one size fits all" approach to population change. New models of social marketing, informed by community-led campaigns to challenge inequality and raise awareness need to be supported through proper long-term resources (French and Vernon, forthcoming).

> **Without improving BME community health, it will be hard to really improve population health and well-being.**

" General approaches to health and social care should be flexible and adapted to the needs of those receiving them. They should be involved in setting aims and objectives in pursuit of health and wellbeing, and not simply be recipients of health and social care that has nothing to do with their situation. "

4 Set mandatory duty for accountability on health equality outcomes

Race equality should be made a target against which outcomes are measured and against which payments are released. For example, the New Horizons strategy states that by 2020 "inequalities for black and minority ethnic groups in access to and experience of mental health care will have disappeared" (DH 2009a). Milestones such as this should be set for other health conditions as well to bring health experiences at least on a par with the national average experiences. The milestones need to be linked to performance targets for primary care trusts, local authorities, mental health trusts and their CEOs. A mandatory duty needs to be established on health and social care services to report on these performance targets and outcomes to service user and community organisations and minority ethnic health forums at local, regional and national levels. Health and social care services have to be accountable to the people using their services.

5 Monitor the commissioning process for effectiveness in meeting community needs

The key objectives of the government's policy of World Class Commissioning are better health and wellbeing for all, better care for all and better value for all (DH, 2009d). The document states that "by putting the patient at the heart of decision making and having a long term focus on health promotion, [world class commissioning] enables PCTs to commission high quality and value for money services, that meet the needs of their local communities." The NHS has a "duty to involve" service users, carers and communities in shaping all aspects of commissioning (DH, 2008b).

While there is guidance around appropriate commissioning, there is no mandatory duty to make this imperative. Monitoring and accountability standards need to be set up to ensure that the commissioning process is actually providing value for money, meeting the needs of local communities and with the leadership of service users, carers and communities.

6 Ensure service user and carer leadership in evaluation of services

At the centre of most health and social care policies (personalisation and recovery are two examples) is the ideology of choice, control and a person-centred approach. User/carer involvement is central in health and social care policy. Over the last few years this has made a huge amount of difference in some areas of service delivery. However, the experiences of service users and carers from racialised communities show that this has remained tokenistic in many areas, and that there has been a gradual decline in their participation (Begum 2006, Kalathil 2009). It is imperative that the future of health and social care services is based on meaningful user/carer leadership.

Standards for evaluating and monitoring health and social care services should be developed by service users and carers. Services should be evaluated against these standards using methodologies developed in collaboration with service users and carers and should be led by them.

7 Recognise and respect cultural heritage, identity and belief systems of communities

In 2010 we must all recognise that we have to be more sophisticated in unpacking the experiences of communities often brought under the term "BME." We need to have a greater understanding of the complexity of racialisation and how culture, gender, age, religion, sexuality, disability and other markers of identity impact on health inequalities and access to services. That is why all public bodies under the Single Equalities Bill must deliver robust race equality and diversity plans to tackle structural racism in their organisations. Without such plans or clear sanctions and accountability, racialised communities will be denied human rights and dignity, further compounding the impact of institutional racism and health inequalities.

Recommendations	Actions	Accountability	Timescale
Address the diversity of identities and experiences within communities while delivering services	▪ Conduct rigorous analysis of the needs of individual communities in local areas ▪ Develop cross-borough multi-agency commissioning of services to ensure that smaller communities do not lose out ▪ Use legal elements of positive action to create diverse workforces ▪ Provide workforce training in flexible, person-centred ways of working	NHS and local authorities with Government offices Government departments, local authorities, NHS Confederation, trade unions, public, private and voluntary sector employers Recognition awards for minority ethnic staff in voluntary and public sector	Jan 2011 March 2011
Develop systems to enable racialised communities to influence policy making at the top level	▪ Set up an advisory board to influence policy decisions ▪ The advisory board to report directly to the Secretary of State for Health and the Chief Medical Officer ▪ The advisory board to represent views of minority ethnic communities through service users, carers and community members	Secretary of State for Health	June 2010 (Meetings four times a year)
Support community-led social marketing campaigns to challenge inequalities and raise awareness	▪ Support community-led campaigns to address stigma within communities ▪ Provide resources for campaigns to challenge discrimination within society and in the media ▪ Create education initiatives to raise awareness about health conditions and about services ▪ Set aside dedicated long-term resources to support these campaigns	COI, Department of Health	Review current campaigns by Dec 2010 Feb 2011 April 2011
Set mandatory duty for accountability on health equality outcomes	▪ Set milestones to end racial inequalities in health and social care ▪ Link milestones to performance targets for PCTs, LAs, mental health trusts and their CEOs ▪ Regular reports to representatives of service user/carer organisations and health forums ▪ Commission yearly independent report on race inequalities in health and social care	Secretary of State for Health, EHRC Department of Health	Jan 2011 From March 2011 From April 2011
Monitor the commissioning process for effectiveness in meeting community needs	▪ Value for money, meeting the needs of local communities and service user involvement to be made mandatory in the commissioning process ▪ Commissioning process to be monitored on standards set to ensure the above	Care Quality Commission and Audit Commission, EHRC	Nov 2010
Ensure service user and carer leadership in evaluation of services	▪ Service users/carers to develop evaluation standards for services ▪ Evaluation of services to be user/carer-led	Care Quality Commission, Department of Health, local government, EHRC	Nov 2010
Recognise and respect cultural heritage, identity and belief systems of communities	▪Conduct ongoing reviews of service delivery and workforce ▪Set mandatory standards for race equality schemes	NHS, local government and other public bodies EHRC	Nov 2010

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