Better practice in mental health for black and minority ethnic communities

Mental Health Providers Forum and Race Equality Foundation

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The Race Equality Foundation promotes race equality in social support (what families and friends do for each other) and public services (what ‘workers’ do with people who need support). We do this by exploring what is known about discrimination and disadvantage, then developing evidenced-based good practice to promote equality. We then disseminate this good practice through educational activities, conferences and written material.

For 25 years, we have worked with the Department of Health in bringing about evidence-based change, for example, in mental health, and supported their engagement with the black and minority ethnic-led third sector. Our evidence-based approach to achieving change has helped us to better understand the role played by black and minority ethnic-led voluntary organisations in the health sector and to gain an understanding of how these organisations can be engaged and supported.

The Better Health practice site includes a growing range of evidence-based briefing papers examining health topics and inequalities experienced by black and minority ethnic communities. The site focuses explicitly on the use of evidence to affect positive change and is used by practitioners and academics in health both nationally and internationally.

www.raceequalityfoundation.org.uk
www.better-health.org.uk

Mental Health Providers Forum

MHPF is the national alliance for voluntary mental health provider organisations. We support more than 60 national, regional and local voluntary mental health organisations, who together provide support for more than 5 million individuals. Our members provide a range of services, including: inpatient, forensic, community, housing, employment, substance misuse and psychological therapies. We provide a collaborative and co-operative voice for the sector and create a platform where organisations can come together to develop good practice and initiate and inspire innovation. In addition MHPF leads a strategic collaboration of voluntary mental health organisations including the Centre for Mental Health, NSUN, The Mental Health Foundation, Mind and Rethink Mental Illness into the Strategic Partners Programme with the Department of Health, NHS England and Public Health England undertaking specific agreed work programmes aimed to benefit the strategic development of the voluntary mental health sector.

www.mhpf.org.uk

Regional Host Organisations

We were assisted in the facilitation and organisation of our regional consultations by three of MHPF’s member organisations. We would like to acknowledge and thank them for their input:

- In Birmingham – Midland Heart
  www.midlandheart.org.uk
- In Bristol – Second Step and their local black and minority ethnic partner SARI
  www.second-step.co.uk
- In Prescot – Alternative Futures
  alternativefuturesgroup.org.uk

Their involvement and local knowledge enriched these local events.
Evidence shows that black and minority ethnic communities have significantly poorer mental health outcomes and poorer experience of services. For some individuals, limited knowledge of available support and the ways to access it allows mental health problems to become more entrenched and difficult to cope with.

The Race Equality Foundation and Mental Health Providers Forum set out to find examples of best practice in mental health for black and minority ethnic communities in order to influence the process of change. We found there are many organisations and projects promoting and tackling issues around mental health in black and minority ethnic communities. They adopt a broad variety of approaches in how they work and who they work with, negotiating relationships with statutory providers and filling gaps where services fail to address the needs of minority ethnic communities. They use their knowledge to develop services that are culturally appropriate, responsive to need and which tackle the issues affecting their communities.

However, many organisations face challenges in meeting the sheer level of need. The relationship with funders is often the most challenging issue for these organisations – for many, a lack of secure and stable funding is a real barrier to maintaining services. Many organisations also struggle to comply with the requirements set by funders around monitoring and evaluation, despite having established reputations for providing good services. For many groups, ‘survival’ is their greatest concern.

It is the aim of this report to encourage funders and the statutory sector to address the challenges faced by voluntary and community sector organisations working with black and minority ethnic communities and to highlight some of the lessons that can be learned from their work around mental health.

Methodology

This report is structured in three parts:

- the first section provides a brief summary of the existing research base in relation to the mental health of black and minority ethnic communities;
- the second section outlines the current policy context for mental health in England and Wales;
- the third section gives the results of a series of interviews and focus groups with voluntary and community groups providing mental health support with black and minority ethnic communities.
Exploring the evidence and assessing the policy background

There has been a wealth of evidence produced over the last 30 years to examine the poorer mental health outcomes experienced by black and minority ethnic communities, as well as a number of programmes to tackle these inequalities. Whilst reviewing all of the evidence is impossible, some of the key issues are summarised below.

Different rates of some mental health issues amongst black and minority ethnic communities

There is evidence to suggest that individuals from black and minority ethnic communities may be more likely than their White British counterparts to experience some mental health issues.

For example, African Caribbean people are three to five times more likely than any other group to be diagnosed and admitted to hospital for schizophrenia, in spite of lower rates of diagnosis for other common mental disorders (Mental Health Foundation, 2015).

It has been suggested these higher rates may be due to a tendency amongst psychiatrists to diagnose schizophrenia when dealing with black males, which has in turn been attributed to explicit or institutional racism, or to a racialised definition of the traits which define schizophrenia (Jonathan Metzl in Lane, 2010). However, an in-depth study into ethnicity and psychosis, the Aetiology and Pathogenesis of Schizophrenia (AESOP) study, (Morgan et al., 2006) suggested that rates of diagnosis may also be attributable to socio-economic and geographical differences. With a higher incidence of psychosis in south-east London than Nottingham or Bristol, the authors suggest that ‘urbanicity is a risk factor or indicator for psychosis’ and that subsequently the concentration of black populations in urban areas may explain higher rates of diagnosis (Morgan et al., 2006).

Mental health issues amongst Asian communities appear to be influenced by factors including age and gender. A study from Weich et al. (2004) found that middle-aged Pakistani men and older Indian and Pakistani women had significantly higher rates of common mental disorders such as anxiety and depression, whilst Bangladeshi women had a very low prevalence of common mental disorders. Another study identified that, as a group, South Asian women had much higher rates of common mental disorders compared to white and black women (Bebbington et al., 2009). Indian men are also reported to have high rates of alcohol-related problems (Mental Health Foundation, 2015).

During the 1980s and 1990s evidence emerged to show that Asian women between the ages of 15 and 35 were more vulnerable to suicide and self-harm than their non-Asian counterparts. They were seen as being two to three times more likely to self-harm (Soni-Rahle, 1996, in Bhardwaj, 2001). This was often attributed to cultural issues such as ‘izbat’ (honour) and ‘sharam’ (shame), issues which were often heightened for second generation migrants by the challenge of reconciling traditional or religious beliefs with the expectations associated with growing up in the UK (Bhardwaj, 2001).

In recent years, there has been a shift and a study from Cooper et al. (2010) suggests that self-harm may now be more common amongst young black women. Although the researchers did not seek to explore the reasons for this in depth, they suggest that ‘young Black females who self-harm may be experiencing greater social adversity, as in our cohort they were more likely to be unemployed and report housing problems’. Furthermore they found that, despite higher rates of self-harm, fewer young black females were receiving psychiatric care than other ethnic groups (Cooper et al., 2010).

Evidence around the prevalence of mental health conditions in Chinese communities tends to be limited, although a 2008 report produced as part of the Delivering Race Equality programme highlighted the importance of cultural concepts of mental health, stating that ‘Chinese older people were unlikely to recognise the symptoms of mental ill health and also unlikely to perceive mental health problems as ailments that required medical attention’ (Tran et al., 2008, p.5). Other resources have emphasised the role of strong community support and an emphasis on holistic and non-statutory approaches to treatment as factors leading to the underrepresentation of Chinese communities in mental health services (Mental Health Foundation, 2015). However, the risk of stigma surrounding mental health means that people from Chinese communities may also be reluctant to seek help. According to the Mental Health Foundation, Irish people living in the UK have much higher hospital admission rates for mental health problems than other ethnic groups, and in particular, are at greater risk of suicide, have higher rates of depression and are more likely to have alcohol problems (Mental Health Foundation, 2015). Ryan et al. (2006) suggest that the relative ease of migrating to England from Ireland, due to geographical proximity and a shared language, may ‘contribute to conflicts with regard to identity and settlement’ since migration is perceived as being only temporary.

Most refugees and asylum seekers will, through the very nature of their position, have experienced trauma in their lives which is likely to have a significant impact on their mental health. Most will have experienced extreme violence or the risk of violence (including war, rape or torture and ‘gender-specific forms of persecution such as sexual violence, marital rape, domestic violence, female genital mutilation, forced abortion or sterilisation’ (ICAR, 2007)) as well uncertainty during their passage to the UK. Dealing with such experiences will be compounded for most by their experiences on reaching the UK, as well as racism and a hostile political system: ‘Those who claim asylum must deal not only with an, at times, baffling and bureaucratic system, but also with the practical and psychological challenges of restarting a new life in a new country, living in a new culture, adapting to new systems and sometimes having to learn a new language’ (Latif, 2014).

Research into the mental health of children and young people from black and minority ethnic communities is limited. However, although small sample sizes make it difficult to draw reliable conclusions (Dogra et al., 2012), there is some evidence to suggest that young people from different minority ethnic backgrounds may have different rates of mental ill health. Green et al. (2005) found that amongst children aged 5-16 years, 9.2% of children from black backgrounds, 7.8% of children from Pakistani and Bangladeshi backgrounds, and 2.6% of children from Indian backgrounds had a mental disorder compared to 10.1% of children from white backgrounds. The research also found some differences in outcomes for girls and boys, with black boys in particular experiencing high rates of diagnosis for conduct disorder.

In a recent briefing, Lavis (2014) highlighted a number of factors which may influence the prevalence of poor mental health amongst children and young people, including family breakdown, parental illness, bereavement, poverty, exposure to racism, low IQ, genetic factors, abuse and exposure to gang culture. Although emphasising that ‘a single risk factor, such as low IQ may not cause any particular problems’ she suggests that the ‘more risk factors a person experiences, the greater the probability that they will develop mental health problems’ (Lavis, 2014; see the full briefing for links to other resources).

There is also evidence to suggest that mainstream services are failing to meet the mental health needs of black and minority ethnic children and young people (Street et al., 2005; Malek, 2011). However, whilst Malek and Joughin (2004) found that children and young people from black and
minority ethnic communities were under-represented in child and adolescent mental health services (CAMHS), these communities also appeared to be over-represented in adult mental health inpatient services. Lavis (2014) attributes this to a failure to provide timely support: whilst most mental health problems start in childhood and adolescence, early support can ‘help build resilience, address underlying problems and prevent the development of more serious mental health problems’. Combined with the increasing number of black and minority ethnic children and young people, in particular, from Eastern European (Lavis, 2014) and mixed heritage backgrounds (Morley and Street, 2014), it appears that the case for early intervention with minority ethnic children and young people becomes imperative.

The relationship between “cultural” and socio-economic issues and mental health

There are also a number of issues which may affect the mental health of black and minority ethnic groups which are unlikely to affect the general population, including forced marriage, Female Genital Mutiliation (FGM), honour-based violence and abuse relating to spirit possession. It is important that such issues are neither seen as widespread in black and minority ethnic communities nor as accepted in or by certain cultures. Forced marriage, FGM and violence and abuse of any kind are illegal under UK law and are condemned as thus by most minority ethnic communities. However, for those individuals who do experience these forms of abuse, there are likely to be severe effects in terms of physical and mental health, as well as difficulties when engaging with health services who may be unfamiliar or ill-prepared to deal with the specific challenges associated with these issues (Bignall, 2015; Philips and Dutt, unpublished for NSPCC).

Black and minority ethnic individuals may also be more likely to experience socio-economic factors which contribute to poorer mental health (Marmot Review, 2010). The Marmot Review found a strong relationship between social gradient and common mental health problems, with a two-fold variation between the highest and lowest quintiles. Factors including deprivation, unemployment and poor housing may all influence mental health outcomes. There is evidence that black and minority ethnic families are more likely to reside in low-income and workless households; live in overcrowded conditions; with poorer pre-1919 housing (Beasor, 2011; Garrett et al., 2014).

There is evidence that black and minority ethnic individuals are 40% more likely than white Britons to come into contact with mental health services through the criminal justice system, rather than through referral from GPs or talking therapies (Kane, 2014). There have been a number of explanations for these differences, whether due to limited awareness of, or a reluctance to engage with, statutory services at an early stage of illness (possibly due to previous poor experiences or the belief that services are not “culturally appropriate”) or the stigma around mental health in some communities. Cultural differences in the way that mental health is perceived may also decrease the likelihood of individuals seeking care before reaching crisis point. This can include ‘different understandings of what constitutes a mental health problem, different cultural expressions of distress including the way symptoms are expressed, and differing expectations of services’ (Kane, 2014).

In a paper looking at the mental health of migrant mothers, Latif (2014) stated that ‘women from non-Western cultures are more likely to present somatic symptoms of depression’, that is physical symptoms resulting from untreated mental or psychological distress. Highlighting the role of stigma in preventing women from seeking treatment, she also argues that ‘in cultures where there is little understanding and awareness of maternal mental health related symptoms, women may not be able to easily identify symptoms or, in other cases, women may understand symptoms but be unable to recognise them or express them’. Latif links this to difficulties surrounding the use of Western models of diagnosis and treatment with black and minority communities, for example, where treatment depends on individuals self-reporting their concerns (Latif, 2014).

Differences in treatment for individuals experiencing mental health issues have also been attributed to ‘cultural difference on the part of the onlooker (the person witnessing distress or distressed behaviour)’ (Kane, 2014), in particular in relation to a number of high profile cases involving African-Caribbean men (for example, David “Rocky” Bennett). Blame often comes from racialised views of black men as being more aggressive or out of control; such views have been described as at best ‘a failure to understand culture’ and, at worst, a reflection of ‘racist views’ (Kane, 2014; see also, Rogers and Pilgrim, 2010; Nazroo and Iley, 2011).

Conclusions

From the brief summary above, the evidence shows that some mental health conditions are more prevalent among ethnic minorities and that this may be due to a range of factors including lifestyle factors, experiences of racism and culturally specific traumas. The evidence also demonstrates that people from black and minority ethnic communities are less likely to seek help at an early stage of illness, due to a combination of lack of knowledge, stigma, inappropriate models of diagnosis and poor experience of mental health services. Black and minority ethnic people also have poorer experiences once in the mental health system and are more likely to be medicated and restrained or risk death in detention.

Organisations working with black and minority ethnic communities around mental health have recognised, and responded to, many of these issues. Understanding their work and highlighting best practice is crucial to continued work on tackling poor mental health outcomes in black and minority ethnic communities.

Current mental health and wellbeing policy context

The Mental Health Strategy in England No health without mental health provides a strategy across Government for improving mental health outcomes (HM Government, 2011), and explicitly mentions race and age as health inequalities that should be tackled. Similarly, the Mental Health Strategy and the Mental Health Strategy Implementation Framework (DH, 2012) recognise the importance of the social determinants of mental health and identify the statutory duties of NHS England and Clinical Commissioning Groups to reduce inequalities in mental health. No health without mental health states that:

‘Reducing inequalities requires a multistranded approach that tackles the economic, social and environmental determinants and consequences of mental health problems. Such an approach needs to take into account the fact that people have more than one protected characteristic. Approaches must also take into account people’s living environments and social circumstances, which are critical to the onset and course of their mental health problems’ (HM Government, 2011).

The Suicide Prevention Strategy (HM Government, 2012) highlights the importance of improving the mental health of specific groups, such people from black and minority ethnic communities. It outlines interventions that could be implemented locally and nationally to improve the mental health of whole communities, and while this is not mandatory for local services, there are relevant criteria in the NHS and Public Health Outcome Frameworks that local areas have to demonstrate they are tackling. At a national level it commits Ministers to tackling race inequalities:

‘A Ministerial Working Group on Equality in Mental Health has been established to ensure that equality issues directly inform strategy implementation. Its initial priority is to tackle race inequality in particular, but it also aims to ensure that the full obligations of the Equality Act 2010 are met’ (HM Government, 2012).

In 2014, the Department of Health’s Closing the Gap report identified 25 ‘priorities for change’. These included the integration of policy relating to mental health with that relating to physical
health; a focus on strategies which emphasise prevention and the need to give attention to the quality of life experienced by people living with mental illness. Two of the 25 priorities related specifically to black and minority ethnic communities:

‘4. We will tackle inequalities around access to mental health services. For example, evidence shows that people from black and minority ethnic communities have to date been less likely to use psychological therapies. We are working with the Race Equality Foundation and other stakeholders to try and understand why this is the case and to understand inequalities around access to other services. NHS England are also working with black and minority ethnic community leaders to encourage more people to use psychological therapies’.

‘21. We will introduce a national liaison and diversion service so that the mental health needs of offenders will be identified sooner and appropriate support provided. To help achieve that, we want to ensure that as soon as someone comes into contact with the criminal or youth justice system, their needs are assessed. For some, particularly young men from black and minority ethnic communities, or those involved in gangs, this may be the very first time their mental health problems are identified and assessed. If a mental health issue is identified, appropriate support should be offered from the outset, as well as further down the line – in court, in the aftermath of an incident or during sentencing’ (Department of Health, 2014).

There has also been an increasing interest at policy level in factors contributing to wellbeing and life satisfaction. Such an approach takes the understanding that mental health does not only relate to specific mental health symptoms or conditions, but can also relate to the presence or absence of positive wellbeing (i.e. that it is possible to live positively with a mental health condition such as bipolar disorder, should the appropriate support and treatment be available).

Measuring wellbeing can be both subjective (based on people’s satisfaction with life overall) and objective (based on certain criteria, for example, external criteria, such as health or income) (House of Parliament, 2012). According to Department of Health (2014) ‘Wellbeing is about feeling good and functioning well and comprises an individual’s experience of their life; and comparison of life circumstances with social norms and values’ (Department of Health, 2014). The Health Survey for England (2012) describes wellbeing as ‘an important element of people’s overall health. Mental well-being is not just the absence of mental ill-health’.

Issues relating to the mental health of black and minority ethnic communities have also been periodically highlighted at the strategic level in high-profile cases and subsequent investigations. For example, the ‘Big, black and dangerous’ (1993) report into the death of Orville Blackwood, or the Bennett Inquiry (2003) into the death of ‘Rocky’ Bennett looked at whether there were lessons to be learnt and changes needed in the treatment of black men in the mental health system.

In 2005, the Government committed to tackling race inequalities in mental health through the Delivering Race Equality (DRE) Strategy, which ran for five years and lead to a number of reports which highlighted good practice in the sector. However, few of the initiatives started under DRE were sustained beyond 2010, with a failure to sustain projects and cuts to funding for the 500 Community Development Workers who had been employed by mental health trusts. Combined with the general impact of austerity on the voluntary sector, there has been a significant decline in support for mental health work focused on black and minority ethnic communities over the last 5 years.

Evidence from practice

We conducted a series of interviews with voluntary and community organisations who were providing mental health services to black and minority ethnic communities. A mixed methodology approach was employed, with a team of four researchers undertaking a combination of face-to-face interviews, phone and email correspondence. Three regional focus groups were also held in Birmingham, Bristol and Prescot. The criteria used to identify good practice focused on evidence of service user involvement in the design, implementation and evaluation of projects by mental health service users from black and minority ethnic backgrounds (either written or oral).

The following section highlights the key themes that emerged from the interviews and focus groups. It seeks to compare and contrast the different approaches, target user groups and challenges faced by the organisations.

Target user groups

There is some variation in the user groups served by the organisations, with some targeting very specific cultural or ethnic groups whilst others take a more generalist approach. In some cases, this may be dependent on the geographical location of the service providers. For example, Sahara is a mentoring organisation which helps to reduce isolation and distress for black and minority ethnic individuals in Devon. With most minority ethnic communities scattered sparsely across the South West, service users may find that they are alone in their experiences and health needs within the region and therefore the organisation can play an important role in connecting them to local services. In other cases, organisations seek to meet the needs of a range of clients despite a diverse local population (for example, Asylum Link Merseyside).

Other organisations work with specific ethnic or religious communities in their locality. For example, the Bolton Council of Mosques runs counselling and mental health advocacy ‘in line with the principles of the Muslim faith’; the Trafford South Asian Mental Health Service works with South Asian adults and their carers, families and communities within the borough of Trafford; whilst Leeds Gypsy and Traveller Exchange (Leeds GATE) works to improve quality of life for Gypsy and Traveller families and communities.

Approach to mental health

The organisations surveyed took a number of different approaches to tackling poor mental health outcomes amongst black and minority ethnic communities. These approaches varied in scope from those which were explicitly oriented towards mental health symptoms and treatment, to those which took a more holistic view of mental health outcomes, as viewed in the broader context of good physical health and wellbeing.

For example, an organisation in Hammersmith and Fulham provides IAPT (Improving Access to Psychological Therapies) services to local black and minority individuals across a large local housing estate. Waterloo Community Counselling work as a subcontractor for Lambeth Talking Therapies and Southwark Talking Therapies (IAPT providers), taking on non-English speaking clients and managing IAPT databases.

Even among organisations which carry out a more explicitly “mental health” approach, there is a strong emphasis on ensuring that the methods used reach the needs of black and minority ethnic communities. For example, the Helen Bamber Foundation (HBF), an organisation that works with people who have experienced severe human rights abuses (including torture, trafficking, FGM, domestic violence, forced marriage) explained that whilst the National Institute for Health and Care Excellence (NICE) guidelines for working with individuals with post-traumatic stress disorder (PTSD)
tend to be orientated towards people who have experienced a single trauma, those asylum seekers amongst their client group have often experienced multiple traumas. They may therefore be better suited to methods such as Narrative Exposure Therapy, an approach that involves talking through someone’s entire life story, but focusing on traumatic events in a way that allows them to process the memory differently, which can in turn reduce nightmares and flashbacks. HBF believe that the approach is more appropriate for their service users, because of the emphasis on story-telling traditions in some cultures: ‘people like the idea of going through their entire life and not just looking exclusively at the traumas which other therapeutic approaches can do’. They seek to employ such formal approaches to therapy alongside ‘a whole range of activities to try to reduce isolation and help people to meet other people and keep them occupied’. This includes creative arts therapy, yoga classes, Pilates classes and acupuncture as well as mind body therapy for individuals experiencing chronic pain after torture.

Likewise, Solace Leeds not only runs traditional one-to-one counselling and psychotherapy, stress management groups, family and marital therapy, but also employs more specialised approaches to cater to the needs of asylum seekers and refugees who have survived torture and abuse, such as massage therapy, pain therapy, acupressure and use of the Alexander technique to address bodily pain and distress. They also employ bibliotherapy, an approach designed to support clients who were authors or journalists, but have since found it hard to concentrate or read because of their experiences. This approach to mental and physical wellbeing is based on the idea that ‘stability and contentment in one area often feeds into another, just as distress does’.

The use of “secondary” approaches which focus on improving the day to day wellbeing of service users appears to be common amongst the organisations we surveyed. Services varied from explicitly health or care orientated services such as a ‘sit-in service to give a break to carers, home care service for elderly, support around the home, washing, dressing, cooking, taking medication, cleaning, companionship, day care service, very vibrant luncheon club, range of activities, talks on health, diabetes, heart disease etc.’ (Dhek Bhal) to ‘social events to encourage integration and friendship... trips and visits to other venues and hill walks... a table tennis team... bicycle repair/ lottery and cycle club, the garden and allotments, Thursday fruit giveaway, home and away cooking demonstrations with other local groups, textiles recycling and student led conversation club’ (Asylum Link Merseyside). Some organisations also provide classes for their service users, including English language (Devon Grapevine, HelpLinks and Southall Black Sisters), tailoring and computer skills (HelpLinks).

Whilst services such as luncheon clubs are frequently held up as fair weather luxuries which have no place within a climate of austerity, many organisations believe that such methods can be more cost-effective than medicalised approaches as ‘a social model takes a more long-term view’ and, ultimately, ‘putting someone on anti-depressants will end up costing more’ (Dhek Bhal). Participants from the Birmingham focus group also believed that avoiding the medicalisation of mental health ultimately, ‘and, therefore be difficult. Within most organisations ‘imaginative initiatives to promote wellbeing’ are also viewed within a public health agenda, either as ‘an antidote’ for ‘the harder grittier casework’ (Asylum Link Merseyside) or as a way to tackle social isolation, particularly amongst people who are ‘new to the country, or for women from certain communities... which don’t encourage women to mix with wider society’ (WaterlooCommunity Counselling). HelpLinks, in particular, highlighted the strong relationship between the ‘confidence or autonomy’ of their service users and good mental health, arguing that for the (generally Tamil) housewives they works with:

“If they learn English, learn to read and write, then maybe they can get a job, make a bit of money for themselves, even just take in some sewing to do in the house and they become a little more independent. This is all connected to their mental health….we can build up their confidence and make them feel comfortable... And it’s all aspects of their lives that contribute to the problem, their immigration status, welfare issues as well as traumatic memories from the war, poor family planning, and this leads to depression, substance misuse, it’s all connected.’

Indeed some organisations suggested that, in the context of the experiences and uncertain lives of their service users, such informal or holistic approaches might actually be more successful than formal therapy. For example, a representative from Southall Black Sisters suggested that amongst women with outstanding immigration issues ‘the priority has to be to deal with their needs, rather than engaging in therapy. Because they are too preoccupied with what is going to happen to them and so they can’t engage fully with the therapy’. Likewise, representatives from Ujamaa argued that they could ‘only help people to cope with issues, [they] cannot provide the ultimate outcome of being believed and protected: only the Home Office can do that.’

An organisation which matches young unaccompanied asylum seekers with volunteer mentors, emphasises that, although ‘not saying anything against traditional kinds of therapy and counselling’, it is particularly important that their service users have something positive to focus on in the future. They argue that providing ‘a reliable adult presence... that is constant and supportive... helps [the young people], through encouraging them in their academic endeavours, to live a more emotionally stable and confident life in their community’. They state that for ‘people who have lived through traumatic experiences, looking forwards and making plans for the future, striving towards the goal of becoming something, achieving something [...] can be really good for emotional wellbeing too. Instead of having to constantly re-hash the past, the children are encouraged to think positively about the future and believe in themselves and work towards that.’

This focus on what individuals can do, and can do now, was seen across a number of organisations, with many seeking to involve former service users in the process of service provision. For example, Helplines encourages women who have taken part in classes as participants to deliver the training themselves: ‘we have women who arrived as service users, and now are teaching the classes’. Likewise, Solace Leeds recruits refugees (who have been granted leave to remain and the right to work) as volunteers, either to interpret for others or to support the running of the service. They believe that ‘this not only gives the individuals some work experience and skills, but also allows them to feel that they are giving something back and supporting others.’

Other organisations seek to encourage participation by their service users in the wider community. Black Health Initiative (BHI) seek to facilitate and support individuals to become involved in local boards and forums, such as patient involvement initiatives. Others encourage their service users to go out and promote the services that they have used. For example, Kadimah is an organisation which works primarily with non-practicing people of Jewish descent. Although in contact with the local Orthodox community, they describe the relationship as ‘delicate’ due to issues of stigma surrounding mental health. The promotion of their services to Orthodox communities is therefore rarely explicit, but instead depends upon ‘people who have benefited from the therapies [going] out into the community to discuss their experiences and raise awareness in the community/educate community elders about the issues.’

Meeting the needs of specific communities

In many cases the specialised nature of the work carried out by voluntary and community organisations plays an important role in plugging gaps which may exist in the provision of services by mainstream providers, tackling culturally specific issues or overcoming shortcomings in the cultural appropriateness of statutory services. In the words of a representative from Asylum Link, ‘available services are very Eurocentric and unsuitable for many of our clients.’ Several organisations believed it was their role to ‘flag and identify’ these shortcomings, making sure that ‘relevant
agencies are aware of the gap in provision’. For example, the young people’s organisation, Act For Change believe that ‘Local Authorities often do not have the clear evidence of specific needs of identified families’ and that by highlighting gaps in service provision they ‘can assist in influencing future service delivery’.

Other representatives said that gaps in service (attributed by some Birmingham focus group participants to the reluctance of statutory services to come to the community for solutions), were the driving force behind the formation of their own organisations. For example, Akwaaba Ayeh, a charity which supports people from African-Caribbean and South Asian backgrounds, was established due to ‘a highly visible gap in service provision, that was evident through the lack of individuals from our communities accessing services on the one hand, and on the other community outreach or work with faith organisations showed clearly that there was a need for support’.

Likewise, the African-Caribbean Mental Health Service (ACMHS) formed to support African-Caribbean communities due to a ‘lack of services that took into account the specific cultural needs in providing mental health services.’ These needs can vary across and within demographic groups and as ACMHS’s service users have broadened in scope, they have seen the increasing ‘visibility of sub groups within that demographic, each with different needs or perceptions of mental health issues.’ At the Birmingham focus group, there was a strong sense that community-led approaches were valuable, and that it was important communities took responsibility for their own needs.

Even where service users did not come from the same or similar backgrounds, there was an emphasis on involving users in service development. It was felt that working with users to shape the services would remove the sense of compulsion which is sometimes apparent in mental healthcare and instead increase a sense of ownership and uptake. Action For Change summed this ethos in three key principles:

- ‘We do not do things to people, but rather WITH people’
- ‘We do not impose solutions on people but rather create the space to ENABLE AND EMPOWER people to seek out their own solutions’
- ‘[we] “go to where people are AT and meet them there” rather than following a “come to us” approach to service design and delivery.’

They also seek to draw their staff, volunteers and board members from a diverse multi-cultural, multi-faith, multi-gender and age spectrum to enable ‘all aspects of the service and project to be informed by the widest possible views and perspectives’.

Methods to ensure services are culturally appropriate: language and training

Many organisations will seek to reach client needs by carrying out specific training (i.e. BHI) or by recruiting staff with similar ethnic backgrounds to their service users (HKMAT, Solace Leeds). Although in some cases service users prefer not to work with individuals from their own community, ‘on other occasions, the experience of the interpreters in traumas similar to those of the clients allows for a better service’ (Solace Leeds). The provision of culturally appropriate services may be linked to language barriers when using mainstream services. Whilst some organisations approach these barriers through a combination of ‘simple written English’ and signposts to ‘partner organisations providing English courses’ (Devon Grapevine), many others employ the use of interpreters (i.e. Waterloo Community Counselling Services provide support in 26 different languages) or bilingual advocates (ASIST).

There was a clear recognition across the organisations that providing interpreting and translation services alone is insufficient, and that interpreters/advocates must also be appropriately trained to work in a mental health context and with different communities.

The Vietnamese Mental Health Service found that most psychiatrists were unable to communicate with clients who did not speak English yet few agency interpreters were trained in mental health interpreting. To tackle such issues, the Staffordshire-based organisation ASIST employ advocates to help service users ‘to understand options, [to] listen to what is important to them…[to] accompany them to appointments to make sure the person’s voice is heard…and [to] challenge professionals not to do health or social care assessments without interpreters.’

Representatives from the Mental Health Champions project at Manor Gardens also emphasised the importance of ‘building relationships [and] taking into consideration language and different ways of doing things’ when working around anxiety and depression with a non-English speaking Somali group, not only employing interpreters, but also making sure that sessions were planned around the needs of the participants (i.e. around prayer time). HBF also highlighted the importance of providing personalised services that give service users freedom over who they work with: ‘a choice of male or female, a choice of language and dialect, and we make sure that people understand that they can opt out if they don’t want to work with a particular interpreter’. Likewise, the BME Residence Group emphasised the importance of ‘a slowly, slowly approach’ and the recognition that ‘women in certain communities would only speak to women.’

Challenging stigma and other barriers

Even amongst clients who do speak English, difficulties in translating the terms used in psychiatry appeared to be common. As a representative from the Vietnamese Mental Health Service explained, ‘they’ve been able to learn about shopping, transport and getting around but when they see the doctor they haven’t the language to be able to explain mental health problems’. In some cases this may be because of a lack of equivalent terms in community languages, whilst in others it may be due to a reluctance to talk about mental health issues. Al Hasaniya, an organisation providing support for Arabic-speaking women, stated that although ‘the language barrier is a particularly isolating one...through developing the service it was clear that there were issues with acceptance and understanding of mental health issues as well.’

Indeed across the organisations we spoke to, it was apparent that language barriers rarely stood in isolation from other cultural factors, and that most organisations also face difficulties in challenging the stigma surrounding mental health issues: in the words of a representative from Helplinks, ‘it’s an absolute taboo in our community’. Attendees at the Birmingham focus group spoke about mental health in the Asian community being perceived in the context of spirituality/black magic, with ‘ideas of possession, “jinns” or spirits taking over the body’. Cultural sensitivity through training for practitioners was seen as essential, since many patients will speak about their symptoms in such terms.

The stigma attached to mental health may also go well beyond the individual experiencing symptoms, and in some cases (for example, in the Orthodox Jewish community) there may be ‘pressure to avoid “exposing” the issue’ to stop it from having a negative impact on the reputation of the whole family or the possibility of finding suitable marriages for the younger generation (Kadimah). It was felt that the role of black and minority ethnic-led organisations as part of the community put them in a unique position to provide support; if individuals relapse or are kept hidden by family members, representatives from organisations would notice and thus be able to take action (Birmingham focus group).
Organisations appear to employ a variety of techniques to overcome stigma, whether by talking about symptoms (anxiety, depression and hallucinations) rather than explicitly mentioning mental health (Armadeep, an organisation working with the South Asian community); by ensuring that their name was not perceived as threatening (the Chinese/Vietnamese Mental Health Project changed their name to the Kwan Wai ("support and caring") Project in 2002); or by delivering mental health services alongside a community café, using food and comfortable surroundings to create ‘a sense of solidarity and sense of home’ (Oremi).

Other organisations rely upon trusted organisations or figures ‘to demystify mental health and counselling processes’, for example, by relying upon the ‘confidence and trust that is directly related to the role of the mosque in a local community’ (Bolton Council of Mosques), by working with community elders (Right Here Sheffield) or Community Health Educators/Champions (Leeds GATE).

In the case of Leeds GATE, there was a recognition that stigma around mental health makes the provision of ‘visible services’ for Gypsy and Traveller groups ‘difficult’ and therefore it was seen as preferable to help ‘the mainstream do what they do better’. There was also an understanding that community ‘champions’ could be trained to discuss health issues and encourage access to services. This training could be in terms of tackling stigma, but also with more practical measures, such as helping illiterate clients fill out forms.

**Partnership working**

Organisations appeared to carry out partnership working in a number of ways. For example, Solace Leeds gain referrals from statutory services, such as ‘health services... other refugee assisting or homelessness groups... from solicitors... through their GP... from local IAPT providers’ whereas the BME Residence Group were mentored by other organisations: ‘Housing trusts and international charities with local offices... gave us advice and worked with us closely.’ Other organisations carry out joint working with statutory services. Action For Change have a clinical psychologist from the Greenwich NHS Youth Offending Team who works with them to take on relevant referrals and acts as an early warning scheme to escalate cases if necessary.

The use of partnership work to help statutory services to better understand black and minority ethnic communities appears to be common. Participants in Birmingham mentioned that newer groups, such as Healthwatch Birmingham, had recognised the importance of the trusted relationships built up by community organisations (i.e. Chinese Community Centre and The Allies Network) and had sought to exploit these when delivering mainstream services. The BME Residence Group (2005-2010) sought to challenge the over-representation of some minority ethnic groups in mental health services through community liaison with local authorities ‘using their expertise to highlight the problem and look for ways to work in partnership with statutory bodies, and especially with the police’. In particular, they recognised that racialised perceptions of mental health amongst statutory providers had led to a significant number of young black men being ‘unnecessarily sectioned’: ‘There would be times when it was clear that the way that someone might speak, for example, like me young Ghanaian men speak loudly to each other... was seen as abnormal and grounds for identifying problems be they health or anything else’. The project sought to address differencing cultural norms, advocate for individuals with mental health problems and tackle the ‘tenuous linking of race, perceived mental health and criminality.

Likewise, Savera, a charity in Liverpool, works with mainstream service providers to raise awareness of issues such as domestic violence, forced marriage, Female Genital Mutilation (FGM) and ‘honour’ based violence. Whilst their main focus is to work within minority ethnic communities to establish community responses, they also recognise that a ‘well-trained mainstream workforce who understand the issues around FM, FGM and honour based violence are in a strong position to help women and girls who need it’. In particular, they emphasise the importance of the ‘one chance rule’, which states professionals may only have ‘one chance to help/support the person at risk’ and therefore should ‘be aware of their responsibilities and obligations’. Complementing the call for NHS practitioners to ‘make every contact count’, such an approach recognises the reluctance of women from some communities to approach mainstream mental health or domestic violence services.

Other organisations emphasise the importance of partnership working with other charities or community organisations. For example, HIKMAT described local partnership work as ‘essential’ in their growth, emphasising the importance of a ‘small but strong community infrastructure’ to help them maintain their services and link with the local community. Likewise, representatives from Sage Sheffield Asylum and Refugee project believed that the close proximity of a night shelter was essential to the success of the Greenfingers gardening project, as destitute asylum seekers trusted the night shelter workers, who in turn introduced them to the Sage Sheffield Asylum and Refugee project.

Music in Detention also emphasised the importance of partnership work with community groups in their area, including ‘primary and secondary schools in areas with high levels of deprivation, youth groups at risk of offending, homeless people, adults with learning disabilities and other mental health issues’. The charity runs music workshops aimed at improving the wellbeing of those detained for immigration purposes and believe that other community groups are not only more ‘likely to benefit from the empowerment and agency provided through the project, much like the detainees themselves’, but also that ‘people with experience of exclusion and stigma are often more able to understand the situation of the detainees really well.’

**Challenges for organisations**

For most of the organisations we spoke to, the major challenge that they face is funding. In particular, short-term funding cycles mean that organisations may find it difficult to plan ahead. Waterloo Community Counselling stated that ‘small organisations like ours are always fire-fighting’. This is a particular challenge where closed communities and stigma exist, as organisations may need to invest significant time and effort in relationship building before they are able to carry out work explicitly focusing on mental health issues: ‘The problem is that it takes time to build trust in communities, to create awareness and then have women being open about the issues’ (Savera).

Organisations also struggled to balance the limited funding that they received with the extensive need that was apparent in some communities; ‘the project budget only supports carers but people come to the service and request help and support for service users, other family members and friends, putting pressure on the service’. One organisation at the Birmingham focus group recognised the importance of staff working overtime to complete work that went beyond the bounds of their funding:

‘The project worker supports service users in his own time and works unpaid on Sunday to cover what he can of the extra work. It’s hard to explain to funders with ring-fenced funds that people come for support outside original project aims and it is very difficult to explain to clients that funding is only for a certain area, they need broader support’.

Some services found that despite their funding ending, service users were still being referred to them: ‘[We] can’t turn people away...Often what happens is that we have to refer people onto assessment services as a lot of people who have left prison don’t have a formal diagnosis and we need to send them for an assessment, which is a big job’ (Plias Resettlement). Other organisations had experienced defensiveness from other organisations, who gave the impression that if community organisations questioned their work, it was only because they were ‘after their funding’ (Birmingham focus group). There was also feelings of resentment in some quarters (i.e.
Santé Mental Health, Birmingham focus group), with the sense that statutory services were using them as unpaid alternatives, without properly compensating them for their work or being realistic about the impact if the organisation is closed. The closure of organisations not only leads to gaps in service, but also to a loss of expertise and severe links to vulnerable and excluded groups. Several organisations at the Birmingham focus group raised challenges relating to funders' expectations around monitoring and evaluation, particularly if the organisation relied on funding from several different sources requiring different evaluation criteria.

Organisations appeared to take a variety of different approaches to monitoring and evaluation. Some organisations enacted a “rough and ready” approach whereby if users “didn’t find things useful, they voted with their feet and their projects failed” (Asylum Link Merseyside, and also Kadimah, Pakistani Resource Centre). Others used a variety of techniques to gain more formal feedback and gauge feelings about the services provided (HBF, Wai Yin). This could be in the form of questionnaires, focus groups or informal discussions.

In other cases, service users were unable to read and write, even in their own languages, so organisations sought to find accessible ways of gaining feedback, ‘we try to have easy to understand forms using happy or unhappy faces... because we don’t want people to feel that they have to modify their answers if they have to fill in the form with the help of a member of staff’ (Waterloo Community Counselling).

Several organisations talked about the burden of carrying out evaluation, whilst focus group attendees questioned who was best placed to evaluate a service: service-users, independent evaluators etc. Some organisations talked about the potential benefits of external evaluation (Praxis: ‘It’s just not doable for a small team with limited capacity’), whilst others found creative ways of keeping evaluation costs down, through offering placements to students to conduct the evaluations (Ohek Bhal). However, there was a sense that funder driven evaluation often failed to take a long-term perspective, and had unrealistic expectations of how much could be done in a limited time frame:

‘Sometimes I feel like it’s like a washing powder advertisement, you know, like people come to PRAXIS and they’re in a very bad situation and then you use the powder and wooh they’re sparkling and new! it doesn’t really work like that’ (Praxis).

Organisations argued that much of the work undertaken by community organisations is difficult to quantify and rarely covered by formal evaluation processes, for example, the empowerment of the service user, the value of the users’ input into the service, or broader cultural and de-stigmatisation within communities (Birmingham focus group).

Furthermore, a lack of awareness about service demand or the specific needs of service users meant that, for statutory services, ‘these people are hidden, and the work... done to support them hidden too’. Many volunteers and employees appeared to work over and above their remit in order to plug gaps in statutory services, yet this often went unnoticed. Representatives talked about carrying out work at weekends or visiting people in their homes to ensure that they reached people who would otherwise be left without support (Birmingham focus group, Praxis).

In many ways this “extra mile” fits closely with the concept of personalised service provision, adapting services to meet the needs of patients, rather than the other way round. Participants in Bristol emphasised the importance of being honest about a lack of knowledge and asking questions to better understand a service user’s needs, rather than making assumptions about individuals or their culture. An NHS worker in Birmingham argued that where community organisations do this “brilliantly”, the NHS is often “hopeless” at taking the extra time to provide sympathy and individual care. Whilst some NHS workers treat mental health care as just a job, community organisations are frequently willing to go beyond “basic” service provision to ensure service users’ needs are met.

In some cases this dependence on the goodwill of volunteers or employees to maintain services in the face of limited funding is problematic. Representatives from the BME Residence Group described how the project closed when volunteers become unable to juggle their priorities: ‘At the latter stages of the project, funding became an issue, but so did the generational shift and the difficulty in passing this work on in this form. I thought it might be because... young people wanted to do something different, but I realised it [was] because they have so many pressures in today’s world. It is difficult for them to find the time that we were able to find with the support we had to make the project work, not just financially, but through our networks and family, being free to look after children for example.’

Generally throughout the sector there was some nervousness about the future in face of ongoing austerity. It has been accurately concluded by Asylum Link Merseyside who emphasised that ‘Survival is high on our agenda.’

Conclusion

Black and minority ethnic communities are vulnerable to a range of mental health issues. They also have poorer experiences when they use mental health services and experience gaps in the provision of services which meet their cultural and linguistic needs.

As a result of these factors, various projects and organisations have emerged to champion black mental health and provide community-based solutions to mental illness. This service provision is often better tailored to the needs of black and minority ethnic communities, meeting linguistic and cultural needs and forming relationships with individuals who might otherwise be regarded as “hard to reach”.

Throughout the project we have been made aware of the volume of undocumented and unrecorded value being added by voluntary and community sector organisations in different localities. This unrecorded work often takes a more holistic view of mental health, linking individuals to local communities and wider society and overcoming some of the challenges and barriers associated with medicalised views of mental health. However, across the sector there appear to be challenges with overwork and funding limitations. A widespread failure to recognise the extent of the work being conducted by voluntary and community groups means that funders and statutory services often take service provision for granted and do not acknowledge the likely impact should organisations disappear. Not only would gaps in service quickly emerge, placing an enormous burden on the statutory sector, but there would also be the loss of experienced staff and the severing of relationships with black and minority ethnic communities which have taken time and trust to establish.

A failure to step in to protect this expertise would have serious implications for the future. Moral, legal and economic incentives should make the mental health of black and minority ethnic communities a priority for funders and statutory services. The concerns raised above should act as a driving force for action to protect the extensive contribution that is already being made by the voluntary and community sector.