National Coalition for Independent Action



NCIA Inquiry into the Future of Voluntary Services

Working Paper 11

Inquiry into the Future of Voluntary Service Support for Black and Minority Ethnic Older People

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Foreword

This paper has been produced as part of the NCIA Inquiry into the Future of Voluntary Services. The Inquiry is specifically concerned with those voluntary and community organisations that deliver *services* in local communities, especially those that accept state money for these activities. These are the groups that have been particularly affected by successive New Labour and Coalition Government policies regarding the relationship between the voluntary and statutory sectors, and attitudes and intentions towards the future of public services. In this and other papers we refer to these as Voluntary Services Groups or VSGs.

It has long been NCIA's contention that the co-optive nature of these relationships has been damaging to the principles and practise of independent voluntary action. The nature and scale of the Coalition Government's political project – ideologically driven - to degrade rights, entitlements and social protections, and to privatise public services that cannot be abolished is now laid bare. This has created new imperatives for VSGs to remind themselves of their commitment to social justice and to position themselves so that they can once again be seen as champions of positive social, economic and environmental development.

Our Inquiry is a wide ranging attempt to document the failure of VSGs, and the so-called 'leadership' organisations that purport to represent them, to resist these shackles on their freedom of thought and action. But it is also an attempt to seek out the green shoots of a renaissance that will allow voluntary agencies to assert their independence and reconnect with the struggle for equality, social justice, enfranchisement and sustainability.

This paper is one of a number that has been produced through the Inquiry and is concerned with the role played by, and effectiveness of, voluntary and public services in tackling the situations faced by Black and Minority Ethnic (BAME) older people in England and Wales. It has been prepared for NCIA by Valerie Lipman, to whom we offer grateful thanks.

For more information on the NCIA Inquiry please visit our website – www.independentaction.net.

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Inquiry into the Future of Voluntary Services Support for Black and Minority Ethnic Older People

1. Purpose of this paper and overview

This paper contributes to the NCIA Inquiry into the future of voluntary services. The paper explores the role played by, and effectiveness of, voluntary and public services in tackling the situations faced by Black and Minority Ethnic (BAME) older people in England and Wales. In particular it investigates the role played by BAME specific voluntary services for older people, how they are faring in the current climate of austerity and public sector cuts, and the part these services might play in the future to address the racism, inequality and disadvantage experienced by older people from BAME populations.

A contradictory picture emerges of how and where BAME older people receive personal support in later life, and their satisfaction with formal and informal care services (i.e. those outside the regulated care system) and community support. On the one hand, an attitude prevails which says BAME older people are looked after by their own communities, families and (mainly) female kin; on the other, mainstream providers of care and support (and other public services) are said to be supporting BAME older people in similar ways to the support they provide to the rest of the older population. Moreover, since the 1980s there has been a continuous refrain about declining family support within BAME communities in England. A Social Services Inspectorate report in the mid-eighties (Prime, 1987) questioned the publicly held belief that "they look after their own", by pointing to the problems faced by family carers; while more recent studies have provided evidence that families are often unable to look after their older members (Victor & Martin, 2012, Nijjat, 2012) for reasons of changing family structures and cultural expectations. In the recognised absence of familial support for some individuals, there is a further history of BAME-led organisations and groups delivering services and support to their older communities as compensatory or substitute mechanisms.

There is a parallel story of positive responses to the different and changing needs of BAME older populations over the years among mainstream services in the public and voluntary sectors. The 1980s and 1990s saw the development of some planned responses to their needs, with the introduction of targeted or specific services, such as religious or culturally acceptable meals on wheels, lunch and social clubs and the introduction of information and advice services with bilingual or multilingual staff and/or access to translated material in different languages and about specific issues. These were usually funded by local government mainly by allocating grants to local community BAME or age specific organisations to deliver the services, recruit volunteers and or to provide community development approaches. A variety of ring-fenced funding or specific government grants became available to support projects for BAME older people, and some mainstream nongovernmental providers of older people services offered specialist support, capacity building and grants to assist BAME groups (such as Help the Aged and Age Concern). There is evidence of a reduction in these services over the last few years linked to withdrawal of funding or the time-limited nature of such initiatives.

It is impossible to discuss this history and to assess the impact of changes on BAME-led organisations and BAME older people without taking into consideration the decades of inequality and discrimination in the UK that many of those from BAME backgrounds have

experienced, and continue to face. These include greater unemployment and lower wages, poverty, difficulty accessing services and entitlements, poorer health and housing, lower educational attainment, and higher representation in mental health services and the criminal justice system, compared to many of the White British community. BAME older people may also experience, what is sometimes termed, 'double jeopardy': marginalised as older people and as coming from a minority ethnic background. To add to this picture there is, what many see as a resurgence of xenophobia and racism, cuts to entitlements and services, privatisation and fragmentation of public services. Meanwhile, Big Society and Localism policies shelve state responsibilities; while economic austerity and neoliberal policies have extended the gap between the haves and have nots.

This paper begins by exploring recent legislation in two major areas of national policy which substantially contributes to the life course experiences of BAME communities: the Equalities Act 2010 and the subsequent Equalities Strategy 2010; and the Health and Care Act 2012. Having set the context, the paper explores how BAME-led voluntary services are faring in the present climate (2014) and how their experiences are impacting on their clients, volunteers, trustees and older clients or members. The paper concludes by considering possible alternatives for ensuring that BAME older people are not rendered invisible in, and by, the wider communities in which they live.

The findings in this paper were informed by secondary research drawing on organisations' websites and reports, research, and government policy statements; and face to face and telephone interviews with senior staff from 12 different organisations. These respondents were from a mix of five national and regional organisations providing research, policy and advocacy about BAME communities in general; two local BAME organisations providing direct services to BAME older people, two non-BAME organisations working with and for older people providing research, policy and advocacy; and a local non-BAME organisation providing direct services to older people, as well as local campaigning. In addition interviews and discussions were held with two university based researchers, and phone interviews were held with two activists/commentators in the field.

2. Who are BAME older people?

BAME older people are not a homogenous group. BAME communities are diverse and older people are an amalgam of their life histories. For this paper BAME older people are categorised as those over the age of 65 years although many researchers and service providing bodies set the age as lower – 50 or 55 – to reflect the presence of greater life limiting conditions among many BAME communities.

Ethnicity is often a contested term. This paper takes the definition used under the Equalities and Human Rights Act, 2010. The numbers of BAME older people in the UK are increasing both numerically and as a percentage of the population. Although BAME older people make up a comparatively small proportion of those aged 65 and over living in the UK, this proportion will rise in future decades as both the different waves of immigrants and those who are British-born age (Khan, 2011). Between 2001 and 2051 the BAME older population is set to grow 12-fold (Lievesley, 2010). This growth will be greater among the well established groups, such as the Indian community, who have grown old in this country. The 2001 census report showed that BAME older people constituted 2.5% of the population aged over 65, and 1.1 per cent of those aged 85 years – around 13,000 people. The number of BAME people aged 70+ is projected to rise from 170,000 in 2006 to 1.9 million in 2051 -

an 11-fold increase (Khan, 2012). The current BAME population aged 65 years and over was predominantly born outside the UK. Ethnic groups with origins in large scale immigration before 1970 have more than 5% of their population aged 65 or older. BAME groups with the largest ageing populations in the UK are Black-Caribbean, Indian, Pakistani and Bangladeshi. In the future, it is likely that the percentage of older people will also grow for other groups which currently have a young age structure, such as Hispanics and Latinos (Orellana, 2014).

There are growing numbers of studies about the lived experiences of BAME older people (covering matters such as health, social care, housing), but there is currently no comprehensive database on the BAME voluntary sector and its services, and no data yet on the impact of equalities legislation on BAME communities and organisations in relation to other groups. An analysis of the census data on ethnic groups by age is not yet available but projections from the 2011 census show that in the future more of this population will be British-born (Runnymede, 2013). Moriarty & Manthorpe (2012) note that much of the information available about BAME older people is based on past, current and conjectured experiential data, on observations by those working in the field and on reports of activities and conferences by those working with minorities. They also suggest that much of the support provided by faith communities to older people at local level is under reported. As well as shortages of data, difficulties exist in assessing the effects of changing policy and services on BAME older people. The ability to gather data in the fields of health and social care is time consuming and expensive both for researchers to collect and analyse, and for small organisations to contribute to or to collect. Comparative data between take-up and effectiveness of services between white and non-white numbers is also often unreliable, as the figures may be insufficiently statistically robust to be meaningful for planning and policymaking purposes (Moriarty & Manthorpe, 2012). However, a variety of research has been investigating social care provision and making direct comparisons of experiences, such as in the experiences of stroke support (Greenwood et al, in press).

Despite the few detailed studies, there is nonetheless a long enough history of BAME older people in the UK to draw out a sufficient picture of the lives of BAME older people as a whole, and of their care and treatment by service planners and providers. Most BAME communities live in metropolitan areas (Lievesley, 2010). Though very low at the moment, the numbers living in rural areas are likely to increase (Manthorpe et al SCIE research). London currently contains the highest number of older people across all BAME groups. Over half of older Black African and Black Caribbean, almost half of older Bangladeshi, Other Asian ¹and Other Black² and four out of ten older Indians live in London. Amongst non-White BAME groups in other parts of the country, East Midlands, West Midlands and the South East together account for almost four out of ten older Indian older people, while the West Midlands, Yorkshire & the Humber, and the North West together accounted for half of all older Pakistanis (Calanzani et al, 2013). The demand for care home places by the BAME communities of England and Wales is predicted to increase five-fold in the next 40 years from fewer than 20,000 places in 2011 to over 100,000 by 2051. This demand will likely be concentrated in London, the West Midlands, Greater Manchester and West Yorkshire (Lievesley, 2013b).

¹ Census category ² Census category

BAME older people have disproportionately poorer health

People over 65 years from 'Asian' and 'Black' ethnic categories are disproportionately affected by poor health and high rates of life-limiting illness and have an increased risk of becoming reliant on others as a result of disability (Ball, 2012; PSI, 1997). Evidence suggests that rates of mortality and ill health tend to be worse in BAME groups compared with the general population and that their health problems are often more severe (El Ansari et al, 2009). Health inequalities may result from many different interlinking factors such as poverty, lifestyle and genetics.

Generally BAME older people possess lower savings and less wealth than their white counterparts. This is mainly because their lower earnings or incomplete contribution records mean they are less likely to have occupational pensions to support their retirement, and they are unlikely to inherit wealth from preceding generations (Khan, 2012). One study (Runnymede 2013) showed that as a consequence of lower rates of employment and lower paid jobs among BAME groups, many of the older BAME population reach older age in greater poverty than the majority population. While 16% of white pensioners live in poverty, this figure rises to 46% of Bangladeshi and Pakistani pensioners and 25% of Black Caribbeans (Runnymede, 2013). Furthermore, BAME people are less likely to have a private pension, even among those in work, and are less likely to own their homes (Runnymede, 2013). Levels of reported loneliness for BAME older people, with the exception of the Indian population, appear to be very much higher than for the general population (Victor et al, 2012): ranging from 24% to 50% among those originating from China, Africa, the Caribbean, Pakistan and Bangladesh compared to the general profile of 8–10% for White British older people.

BAME groups also experience specific health inequalities, with different conditions often experienced by different groups. For example, Type 2 diabetes is up to six times more common among African and African-Caribbean communities; death rates from heart disease are two to three times higher in those of South Asian descent; while death rates from stroke are three times higher in those of African and African-Caribbean descent. People from BAME groups stay in hospital for longer (Department of Health, 2011). They are often less likely to seek medical help as early as the majority White population and thus are diagnosed later. This results in disproportionately higher mortality rates than people from non-BAME communities living in the UK. Bangladeshi and Pakistani communities are, for example, characterised by high levels of morbidity, deprivation and social exclusion compared with other minority groups and the population generally (Victor & Martin, 2013).

The Social Care Institute for Excellence (SCIE) has acknowledged that there is little understanding of the mental health needs of BAME older people, which are consequently rarely addressed in mainstream health services (Moriarty, 2005). Practitioners likewise acknowledge they have little understanding of these needs and are insufficiently supported in this area (Manthorpe et al, 2010). The same can be said for dementia: South Asian and Black Caribbean populations represent the largest ethnic minority groups in the UK, yet the evidence on dementia care in these communities is profoundly limited (Jutlla & Morland, 2007). Barriers to using health services are many: BAME patients and family members may hold the belief that nothing can be done, lack awareness of available services or how to access available services, experience services that are inadequate, inaccessible and culturally insensitive, including a poor experience of services and stigma attached to mental disorder (Department of Health, 2011).

Stereotypes and marginalisation

Overall, extensive evidence shows a paucity of understanding by planners and service providers of minorities and of appropriate service provision, contributing to the isolation experienced by some BAME older people (Moriarty & Manthorpe, 2012). Statutory services in parts of the country with higher BAME populations provide specific services, translation and interpretation facilities for minorities in their area and have made explicit reference to the BAME older communities in their Older People's Strategies (Manthorpe et al, 2010). In public policy, such as the National Service Framework for Older People (DH, 2001) BAME older people were specifically mentioned, however there is little in the National Dementia Strategy (Manthorpe, in press). However all those interviewed for this paper commented that services have consistently failed to recognise the needs of both longstanding and emerging BAME older people in Britain.

Some families are not able to cope, often because of their own experience of migration and changing family values. The children who have grown up in the 'new' country have adapted to a new way of life, and the grandchildren may not be fluent in the language of their grandparents, adding to difficulties in communication between the generations.

Grandchildren may be participating in activities that their grandparents would never have allowed in their home country, and support for the older person may become secondary to work and school schedules (Nijjat, 2012). In areas with a relatively small BAME population, the needs of minorities tend often to be invisible as these populations can be widely dispersed. As a result, disadvantage and exclusion can be significantly amplified, especially for older people who may already be at greater risk of isolation because of their age (Ball, 2012). Advocacy, representation and interpretation services are important areas of activity for BAME led organisations, but they remain poorly funded (El Ansari et al, 2009).

Traditionally there has been little support from mainstream voluntary services either to the BAME-led sector providing support for its older communities or directly to BAME older people (Ware, 2013). McLeod et al (2001) commented that:

"Mainstream organisations are failing to tackle adequately the deprivation, social exclusion and discrimination experienced by black and minority ethnic communities."

Support from such bodies was generally confined to time limited projects, without long-term integration in the mainstream of services and advocacy. Targeted programmes seek to increase take-up of people who traditionally underuse the services, and to provide a culturally sensitive service that is both needed and wanted. Action for Blind People, for example, recently received three-year funding from the Big Lottery for an eye health project for Black and Minority Ethnic communities in Leicester, Derby and Nottingham (Action for Blind People, 2013).

The stereotypes that BAME communities 'look after their own', or 'want different things from the White mainstream populations', not only gets in the way of providing services but fails indeed to recognise differences between different BAME communities, such as differences in life expectancy and health conditions. Community support is never more needed than in isolated groups where older people are particularly secluded and are in small numbers.

In this context, this study explores what is happening to community services set up by BAME-led groups working from within BAME communities and catering directly for the needs and interest of BAME older people. Needs, preferences and experiences differ between communities, and, as a respondent noted, between those who arrived in the UK in adulthood and those who are UK born or arrived in early childhood. This changing landscape of BAME communities in the UK, containing a greater mix of communities and life experiences, will need to be matched by different policy responses within the voluntary and community sectors as much as in other public spheres.

3. Race, inequalities, health and social care

For BAME older people, combined changes in recent legislation in race and equalities, and in health and social care, present different risks and opportunities for discrete, differentiated and affordable services. While the fundamental issues inherent in both areas of social policy are not new for BAME older people, some people consider that the government's Equalities Strategy 2010 is likely to emasculate the equality/race enforcement of previous legislation (despite its inclusion of age as a 'protected characteristic' in the Equality Act 2010), and the Health and Social Care Act 2012 is likely to result in an intensification of undifferentiated services for older BAME people.

Race and equalities

The Coalition Government's 2010 Equalities Strategy claims a new approach to tackling inequality: one that moves away from treating people as groups or 'equality strands' and instead recognises that the UK is a nation of 62 million individuals (HM Government, 2010). It aims to tackle the 'causes of inequality and [to] build a stronger fairer and more cohesive society' (Government Equalities Office, 2010). The Strategy takes as its starting point the Equality Act 2010, developed by the previous government. This replaced anti-discrimination laws with a single piece of legislation to make the law simpler and to remove inconsistencies. It introduced the concept of 'protected characteristics' ³ whereby the characteristics of these groups cannot be used as a reason to treat people unfairly. For example, it would be unlawful for a voluntary organisation that rents out its kitchens at reduced rates for older people's lunch clubs, not to rent it out to Indian groups, because the other groups say they don't like the smell of curry.

Under the Public Sector Equality Duty (PSED), introduced by the Act, public bodies will be required to publish more information on equality than previously and to demonstrate how they are delivering improvement, 'replacing bureaucratic accountability with democratic accountability' (HM Government, 2010:9). Any organisation that is carrying out public functions on behalf of a public authority, including private bodies or voluntary organisations, will also be obliged to promote equality in the design and delivery of its services. Based on the information it collects from service provision, organisations can take special steps to help groups disadvantaged on the basis of their protected characteristics.

Previous UK equalities duties required public bodies to take a proactive approach to the

³ Formerly only race, sex, and disability were covered by anti-discriminatory legislation. Six additional areas were added under the Equalities Act 2010: age, gender identity & gender re-assignment, pregnancy & maternity, sexuality, religion or belief, marriage or civil partnership.

elimination of unlawful discrimination. The new system appears to be more concerned with monitoring and reporting on what is happening, than removing the patterns and incidents of inequality. An early review of the PSED, commissioned by the Government Equalities Office in 2013 reports that both the private and public sectors held strong views that, regardless of the Duty, equality and diversity considerations should be part and parcel of good service delivery (Hayward, 2013). Putting this into practice was quite a different story. The report showed that many public bodies were adopting a formulaic, 'tickbox' approach to procurement and commissioning processes, and were not actually embedding equality into their practice. The review further showed that the new system had created barriers for smaller companies and charities wishing to tender for public contracts (Hayward, 2013).

Health and social care

The Health and Social Care Act 2012, has been regarded as implementing one of the most radical reorganisations of health care provision in the UK for over 60 years (Ham et al, 2012). Three features dominate. First, publicly provided health and care services are to be brought closer together by integrating personal and health budgets. Second, a new commissioning model has been introduced that places responsibility in the hands of GP-led local Clinical Commissioning Groups (CCGs). Third, patients are to have a greater voice in the design and delivery of health care. Underpinning these features are the government's stated aims to increase independence from central government, promote patient choice, and to reduce NHS administration costs. These changes are viewed by many as a means to remove social entitlements and to privatise the NHS by forcing local decision-makers to allow the private sector to bid for NHS services (Tallis & Davis, 2012).

Many people already do not have a clear idea of what social care is, how it is organised, funded, assessed and how it relates to other services (Independent Age, 2013; Bottery & Holloway, 2013). They don't know how or where to access the information that would help them plan and prepare at key points in their lives, or support them to make choices. In social care this is a particular problem since decisions affecting care and support are, to some extent, subjective (Independent Age 2013:24). This has added pertinence for BAME older people who are already under-using public services to which they have entitlement. The more complex the system, the greater the need for independent support to help people navigate it with advice or advocacy. A national annual survey in 2010-11 of social care users showed that non-white groups say they find it harder to get the information they need (Health & Social Care Information Centre, 2011). For those with language difficulties there are yet greater problems getting around the system:

"In attempting to navigate the social care system, individuals turn to their immediate network of support – their family, friends, GP and community/advice groups. However these individuals and organisations are often themselves confused by the system's complexities' (Independent Age, 2013: 18).

The Care Act 2012 may create a greater need for support workers or volunteers who can, not only translate and interpret material, but understand and access the new system itself.

Future providers

The Government has made it possible for any organisation, whether private or public, which has the capacity to deliver innovative and responsive services, to take part in the delivery of

health and social care. But resources to commission these bodies are limited and reducing. Small organisations and voluntary bodies serving specialist interests are unlikely to win contracts from overstretched, under-resourced CCGs whose main driver is to 'balance the books'. Thus opportunities for subtlety, in providing a range of services and the means of their provision, become harder to create. Statutory duties under the Health and Social Care Act 2012 have been placed on CCGs to determine local health needs, promote equalities, work with local authorities and involve patients and the public. There will be no national programme of clinical priorities for health care. It is incumbent on commissioners to ensure their practices are fair and that they allow a range of suppliers to compete in the marketplace. Again, the focus is on getting the process right, rather than looking at patient outcomes of any actions, if indeed some actions have been taken.

Making it personal

The government says it aims to increase personal choice in a range of spheres such as social care and health services through 'personalisation'. Personalisation could be viewed as bridging the gap between contracts and quality of service. But meeting individual need through sharing the responsibility between the provider and the 'consumer' without sufficient budget seems difficult to realise. The stated aims of personalisation are both about process and the end result, by working with the individual to meet individual need in ways that enhance choice and individual aspiration, and to do this through 'co-production' and sharing responsibility with individuals, groups and communities for what is available. Local authority commissioners argue that personalisation will both enable people to get what they would like from their own community, and prevent them from having to be dependent on statutory services. For example, a person could spend their personal budget on the cost of taking a taxi to a voluntary group's day centre or on a Personal Assistant who speaks their first language and will help them attend a community celebration.

4. BAME-led services for older people

Projects targeting different specific groups have been described as providing 'a lifeline for people who have no one or have no idea what is out there' (Smith, 2011:19). Moriarty & Manthorpe, (2012) further highlighted the value of these services for providing opportunities for older people to contribute as well as receive. The lower take-up of mainstream public services among BAME older people has contributed to BAME-led VSGs developing to occupy the space left by statutory services and by mainstream voluntary services. McLeod et al (2001) noted the significant role played by BAME VSGs in local communities and the delivery of services, particularly for those people with major unmet social and economic needs – those who are lonely and poor.

Community organisations of all sizes, serving different minority groups, have developed: some are very small serving just a few local authority wards, some cover local authority areas, others are regional or national. Some are stand-alone BAME services for older people. But in the main they are part of other BAME organisations providing a range of services for different populations within their communities. Such groups offer social meeting places, access to news about their communities, a sense of belonging and a place where they will be understood - in terms of their language and culture.

Those interviewed for this study described the benefits of services that are designed for

their older members. These included helping BAME older people to articulate their needs and preferences; offering support, information, advice and advocacy in a range of languages; providing social contact and stimulation, reducing isolation and loneliness, providing care services such as bathing and nail-cutting, promoting health and nutrition. They also seek to influence the provision of services locally for BAME older people and creating cultural awareness among service providers. In the main there is little difference in essence from the services provided for the majority population with the important exception that these services and their accessibility take into account the differing cultural needs of the BAME groups, which are not always being met by mainstream organisations. There may be the occasional specially targeted programme or project, but these tend to be short-lived and respondents note that these are sometimes not connected to the wider BAME community from which participants are drawn. The BAME groups are thus helping rectify imbalances in the receipt of services and articulate the needs of BAME older people. Interestingly there is little information about the governance of such bodies and their inclusion of older people in their own assessment of need or power structures.

BAME service providers say that because they work closely with their clients, they are familiar with an individual's background and circumstances in a way that many of the larger providers are unable to achieve. The gap on the part of the 'mainstream' organisations is believed to be a result of inadequate needs assessment procedures - in terms of both the assessment and the assessor, who may be unfamiliar with the nuances of a different culture (although the social care and NHS workforce is overall diverse in ethnicity).

Ethnic-specific public-oriented services, such as community centres, not only offer ethnic minorities a place to get together, but also allow them to 'navigate wider public and universal services' (Runnymede, 2012:20). Contact with such groups, other relationships, access to friends and family, may influence a person's choices of where they retire (Khan, 2012b) or live in later life. Such opportunities and connections are vital. Manthorpe et al (2010) suggested that people do better if they are less isolated and are able to contribute, volunteer or take part in their communities.

5. BAME-led voluntary services

Keeping pace with the changing nature of the BAME sector is an issue in itself. There is no agreed definition of the sector (Ware, 2013), nor national database of information on the sector (Olulode, 2014). Estimates of the number of BAME third sector organisations, serving all age BAME populations in England have ranged between 5000 and 11,000 (Voice4Change, 2007). Much of this large variation in the figures has been attributed to 'out of date information' (Singh, 2010:4). Survey results, used by McLeod et al (2001) challenged the common perception at the time of the BAME voluntary sector as consisting solely of small, informal organisations, living a hand-to-mouth existence. They found that over 50% of the voluntary organisations had an income of £50,000 - £250,000, and over 60% had survived for over 10 years. Several regional bodies possess data about the size of the sector in their respective regions and have been able to assess how BAME organisations are faring in comparison to mainstream organisations. This research found only one national study, by the Afiya Trust (2012), which has sought to compare the impact of cuts on BAME groups

with mainstream organisations⁴. Their study found that one in five of local authorities said that they did not collect the data on BAME voluntary and community sector organisations' funding: a finding that simply underscores the lack of information, and possible interest, about the interests of BAME communities.

The BAME-led voluntary sector is generally seen to have acted as a conduit between the individual, the state and public services: enabling people to gain their rights and access health and social care, housing, benefits and meet specific cultural needs. McLeod et al concluded that:

"Black and minority ethnic organisations comprise a distinct sector within the wider voluntary and community sector because of their origins and their propensity to deal with issues of social exclusion with a racial dimension." (see JRF Briefing, 2001).

Without others to mediate, those already vulnerable are reported to be more likely to suffer from poor health with undiagnosed conditions, poverty, inadequate social care, and isolation.

The development of the BAME sector in Britain has been strongly dependent on the conditions and contexts that people from minority communities encountered when they arrived in the UK. Since the arrival of the first large groups of immigrants in the 1950s, many communities have developed their own organisations and support for their respective groups. Despite the growth of BAME groups, the state never formulated a coherent policy towards such groups or activities. A first step came in 1999 when the BAME Compact Code of Practice was developed in consultation with the sector, but, as Singh (2010) noted, this was not part of the mainstream national and local Compacts and the government message was therefore one of separation and difference, not of understanding and improving access to the mainstream. Several years later, a revised document 'Compact 2009', removed the government's obligations to the BAME sector and focussed entirely on improving the contractual relationship between the government and the third sector (Singh 2010).

The evidence from the interviews and secondary research shows that funding has been reduced for BAME-led organisations and groups locally, regionally and nationally compared to mainstream 'white' organisations (Singh, 2010). The decline in support, a respondent from a national BAME body commented, started under the Labour government as it opened a debate about how 'multi-culturalism has failed' and has intensified under the current government, using the riots of summer 2010 to bolster its views. A 'cohesion versus multi-culturalism' debate appears to be providing a *post hoc* rationalisation for the cuts, as well as bolstering institutional racism/discrimination. It is seen as providing the government and other funders with a narrative that says that generalist is better than separatist, and that in times of hard decisions, where there is less money around, mainstream services/activities are to be prioritised, while funding for smaller minority interests falls by the wayside.

A report from the North East of England on the development of the Black voluntary sector found:

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⁴ The Afiya Trust examined the impact of cuts over two financial years (2010/2011 and 2011/12) on BAME-led VCSOs and service providers to BAME communities. All local authorities were invited to report on their Equality Impact Assessments and compliance with relevant public sector equality duties.

"...that the contemporary policy focus on cohesion and amalgamation of race equality within the broader equality agenda has further marginalised BAME organisations." (Singh, 2010:27).

While public bodies talk about increasing participation by BAME populations and organisations in policy development and capacity building, according to Singh, this avenue has ended with an imposition of 'cohesion' guidance on local authorities and other public bodies, with an implicit message that funding single equality organisations could be divisive. There appears to be no answer to the question about why it is that fulfilling race equality commitments should prove divisive, *if* there is a wider commitment from the government to race equality (Singh, 2010).

BAME voluntary and community organisations have consistently faced multiple barriers in effective and meaningful participation in policy discussions and decision-making, especially in parts of the country where their numbers are smaller (Khan, 2010b). Some respondents commented that not only do consultation processes often feel tokenistic but that they feel 'consulted out' and let down because nothing changes for them at the end of another round of consultation (an experience which is not confined to BAME groups). This exclusion from policy debate and influence is compounded by the nature of BAME work. Rural BAME people are rarely consulted on policy and service delivery and often have little or no involvement in local governance structures of statutory and voluntary bodies (Ball, 2012). The 'claw back' on the BAME sector is leading to much debate within the sector about how it can secure a future capable of addressing the needs and interests of its communities.

Three issues came to the fore in this study:

- the practical survival of the sector itself;
- the political and practical measures it could take to achieve this; and,
- the changing nature of BAME communities and their older members in the UK.

Some respondents commented that there was nothing inherently wrong in organisations raising income and acting like small businesses. One respondent said that in order to survive and be a meaningful provider they would need to be in a position to either compete with the larger players, adapt themselves so that they could become such, promote themselves as a niche provider or help create a mechanism that recognises 'our worth and the special contribution we can make' (Olulode, 2014). Pragmatism was the order of the day: engaging with the government agenda, while being strong enough to stand back and critique what is being 'thrown at' the sector. In terms of the changing communities there are also much larger and longer term debates still to be held about how the needs of older people should be met in the future, as new cohorts have different life experiences and expectations. Preparing for the changing demography of BAME older people is something that goes wider than the BAME sector and requires the wider population to engage in discussion.

Because of their development, BAME-led organisations have largely worked with people from their own communities and are therefore seen by funders as specialist organisations, lacking the ability to extend themselves beyond the interests of their members (Olulode, 2014). This perception may have acted as a factor in restricting the organic growth of an organisation and so providing an effective barrier to its participating in contracting opportunities. Such marginalisation doesn't have to mean that growth is restricted: and indeed adopting this line of thought could result in a self-fulfilling prophecy. Indeed, there is

a view that such marginalisation is positive, as it safeguards BAME and other community groups from the damaging effects of public services contracting and commissioning and increases their chances of survival by remaining outside the mainstream regimes (Davidson & Packham, 2012). Alternatively there were signs that the BAME voluntary sector was willing to 'play' the contract game in order to survive and grow. This study learned of a London-based BAME organisation that is planning to extend its specialist services for older people outside its ethnic group. This was being regarded as competition by the traditional mainstream white organisation which had historically provided these services.

In summary BAME groups working with older people could be said to have been good at providing culturally appropriate conviviality and company; influencing and gaining access to mainstream services; but have had less success in tackling racism and inequality and improving circumstances for the overall betterment of the lives of their older people (Ware, 2013).

6. The impact of recent changes on BAME older people

The withdrawal of funding from BAME-led organisations is resulting in closure of services and cessation of activities for BAME older people, although the evidence for this is often anecdotal. Age UK London reported that organisations working for a single BAME population, such as a Latin American group in South London, are being phased out by funders. There are exceptions. The director of one London-based voluntary organisation reported that its local authority was continuing with the traditional grant system to smaller groups, but acknowledged that this was unusual in London. Without equalities funding or external pressures to prioritise equalities, local authorities and others are saying that work can be integrated, resulting in an undifferentiated approach to people's knowledge, ability to access services and to their different needs. Older people with language difficulties and lack of knowledge of the systems are removed yet further from services that they may need. This is not the way to meet the government's own guidance of treating each older person as an individual with dignity.

It was stated repeatedly by those interviewed for this study, that once a BAME group or organisation goes there are few comparable options for BAME populations. This is no surprise - by definition these groups are minorities and hence having alternative services or activities to attend will be limited. As a result some people may be losing the availability of a hot meal, company, access to resources and vital information. Agencies working with BAME older people have commented that general health and care needs may be compromised by the loss of help from those who can facilitate access to services for them, by loss of their own language speakers and/or interpreters (whose services have also been cut). Life also becomes more expensive if they have nowhere to go. A recent Runnymede debate with BAME older people (Khan, 2012) heard stories of people having to spend all day in libraries and pubs because they cannot afford to heat their homes. People were also said to become silenced once access to their representative bodies ceased to exist. For example, when a club closes down, how are the voices of those members to be heard or accessed by policy makers and planners?

It is equally difficult for the smaller organisations that do survive. With reduced resources they are having difficulty finding the time and capacity to remain involved in wider debates about the provision of services. And though seen as something that statutory bodies are

expected to do with local communities, resources for this type of engagement are generally not available (Manthorpe & Moriarty, 2012).

Small BAME groups (as with all small groups) are struggling to keep going. Small amounts of money make all the difference to community groups - accessible grants from local authorities are helpful in supporting local activities. Groups that have chosen to continue without public funding are mostly self-funded, but at very low levels with a high dependency on the community contributing many voluntary hours. Their success in this depends on the history of the group in this country, their length of time here, their confidence in being seen to be independently minded, their ability to have developed 'social capital' and the funds that are available in that community.

The advent of personalisation and the changes to funding for social care services are said to offer some opportunities for promoting BAME older people's wellbeing. This may be so though the challenges will be many given the limited success to date in meeting the needs of BAME older people. On the one hand, personal budgets and direct payments are seen as offering a wider range of choice to BAME older people and more personalised ways of arranging services that could promote wellbeing. On the other, many BAME older people meeting eligibility requirements for social care (especially those who are isolated and who do not speak English fluently), have limited knowledge of how to access support. They are also dependent on sufficient resources, well trained staff, enough staff, and the existence of options. And these options, in the form of community support and social clubs or day centres are being curtailed. An interviewee from a local generic community organisation commented that the current emphasis on integrated care i.e. the proposed merger of parts of adult social care budget with the NHS is likely to result in a health/medical lead on service provision. Because the NHS has greater resources than social care services, it is likely that health support services will dominate, hence ignoring the care part of a package of support services often provided by smaller community organisations. The caveats for turning the opportunities into meaningful responses are huge. Without the ability to distinguish between different individual and group interests or the information that could show the similarities and differences among minority groups, there is little possibility that policymakers and commissioners will be able to meet different needs.

Small local BAME organisations may need support to enable them to take on new advocacy and brokerage roles if they are to continue to be financially sustainable (Age UK, 2012). But all this misses a key point. On average personal budgets are very low (between £50-100 per week) and the eligibility criteria often so tight that they allow only for basic care. This does not allow for social activities, networking, and the collective voice of minorities to be heard. For example, a BAME service provider in London providing day centre activities for older people commented that the personal budgets their members were receiving were so small that they could no longer afford to come to the centre, instead they were using the budget for home care services. In consequence their members have lost out on socialising and accessing information and advice.

There is little evidence of those mainstream voluntary organisations who work with older people tacking up any slack. Age UK (formerly Age Concern) for example, had for many years provided a national specialist role to promote BAME work. It recently deleted this post and its Equalities and Diversity Unit. The public arena is one of competition rather than co-operation, which has only been reinforced by a culture of contracting for services over the last 25 years.

7. Self-determination versus organisation dependency

Several suggestions were made in the course of this study about different ways of addressing the interests of BAME older people in the light of diminishing services and attention to their different interests. In the main these focussed on increasing the collective and individual voices of BAME older people. Organisations working with BAME older people noted from their research with minority communities that older members want a larger influence on service design. Programmes in development included providing BAME older people with the means to influence the design and provision of local services, as well as enabling individuals to speak out for themselves (Ball, 2012). Another group expressed the view that they could help other providers make their services more accessible to BAME communities (Voluntary Action Leicestershire, 2012).

It was suggested that easily accessible small grants programmes should be made available for voluntary minority groups to support communities to look after their own older people. Local authorities should build trust with minority groups so that they are comfortable about asking for support and to thus assist people access mainstream services. Victor & Martin (2012) suggested:

'Social care based services for Bangladeshi and Pakistani elders may be more appropriate and acceptable if they focus upon helping and supporting families to care rather than being viewed as substitutes or alternatives'.

Others have suggested that the way forward to consolidate the position for BAME older people would be for the larger groups to follow the path of much of the voluntary sector and take on more commissions and become contracted service providers. They could secure a future by extending their activities and working outside traditional local authority or health boundaries. But this might replicate the very problems that the mainstream voluntary sector has fallen into - getting them to do work they don't want, work they may not necessarily be trained to do and take them away from their core business, such as running social clubs and enabling older people to network. The role of the mainstream organisations was also questioned. It was suggested that they too should play a role in supporting BAME older people, by undertaking necessary research and advocating for their interests.

8. Conclusions and ways forward

BAME voluntary services have been essential in looking after and highlighting the interests of their communities. As the state reduces its role, the BAME sector is faring disproportionately worse and the volume of services for older people is diminishing. One respondent noted that the retreat from naming and shaming racism, led by an establishment unwilling to be challenged, is creating the space for public institutions to be unashamedly racist.

BAME-led groups are perhaps caught more than others in the traps facing the voluntary sector. As marginalised groups they are more vulnerable than mainstream bodies. In the absence of so little support for their older constituents should they feel obliged to fight for whatever funds are available and thus collude with government changes affecting

voluntary services? But if they do not 'play the contracting game' and go under in the present climate, who will stand up for BAME communities, and their older people? One respondent commented that this very fight for survival has resulted in a lack of leadership from anti racist organisations (Chouhan, 2014).

This research has found that there is still a need for service provision for BAME older populations. Additionally the experience and knowhow of those who work with BAME older people is seen as critical in being able to assess the needs of their communities, and attempt to influence mainstream and other voluntary service providers. Future cohorts of older ethnic minorities will have different experiences and needs, based on whether they were born here, when or whether they were migrants and the reasons for that move. Potential service providers could learn from BAME providers.

It is difficult to see how the current government changes will improve the position for today or tomorrow's BAME older populations. Large contracts are unlikely - to use the language of the market place - to meet 'niche' market needs, because financial returns will be small. Equalities will not be achieved in a climate where 'tickboxing' processes rather than assessing outcomes are all that is required by government. Large scale mainstream government and voluntary services projects on tight and diminishing budgets will not have the capacity or flexibility to meet individual needs. To suggest, as government and mainstream bodies do, that personalisation will be able to deliver authentic control and choice is misleading at best. If the resources do not exist, no amount of joint working, user involvement, or co-production is going to result in a tailored package of care and support that both suits and fits the client. It also contains a sleight of hand which makes the 'user' share the responsibility for an inadequate package of support.

Despite the rhetoric of equality, and the requirement under the Equality Act for all suppliers to the public to meet equality criteria, BAME older people will not be better off, and are more likely to be worse off. Contractors will not meet small-scale needs, voluntary organisations who could possibly offer appropriate services are not winning the contracts. Little has been learned from the gaps in historic public services where developments facilitated by specific grants at least offered scope for direct help. Depressingly, it appears that whatever sector - public or private - is responsible for meeting the needs of BAME older people, questions of race and cultural incomprehension need to be addressed, and the rhetoric of each sector critically examined as part of planning, so that intentions can be realised.

Divisions are becoming present between local authority commissioning and operational practice. If the concern is with the 'bottom line' and there is no experience or interest in service delivery, or of those who use services, a breakdown of confidence between commissioners and the providers is inevitable. Short term financial horizons appear to prevail and, if cost and volume matter most, there is likely to be little time, or interest, given to find and understand good practice evidence. Commissioners may rarely encounter 'real people' willing to challenge their assessment and decisions on what is needed and who should provide it. New contracts between statutory commissioners and voluntary sector providers are unlikely to meet 'niche 'markets' or provide support subtle enough to meet different needs (a local health organisation).

The fundamental story for BAME older people in this country has barely changed over the last 30 years. Their interests have not been mainstreamed into the work of the larger

providers, by either local authorities or the voluntary sector. There have been moments when the picture was more hopeful with funding to support a wide range of groups and a political environment willing to acknowledge and support difference. The current political climate of 'integration and cohesion' suggests that difference is to be hidden, and thus limits the subtlety required in policy making and planning that would facilitate a diversity of provision able to serve the needs and dignity of a mixed population. The voluntary sector which could play a valuable role in supporting and advocating for BAME older people has also been somewhat distorted by bureaucratic and market-driven agendas of the public sector, resulting in a loss of support and active engagement with BAME older people .

Crucially the absence of hard data, or rather its invisibility, relating to the needs and aspirations of BAME older people result in a gap for those planning, designing and delivering services, if they were so interested, as well as for the beneficiaries themselves. While there are acknowledged gaps in data relating to the interests and needs of BAME older people there is enough experience to respond appropriately if there is sufficient will to do so. The real gap is the resistance to countenance change in a system which does not want to recognise differences. The picture that emerges is overwhelmingly reformist with the message of 'business as usual'. Calls for 'building trust', 'making services more accessible' and 'person centred support planning' have been happening with no significant impact. On the other hand there is evidence of growing self determination: through direct voices/action and through self sufficiency for BAME groups, on the grounds that 'we'll need to look after ourselves because nobody else will'.

There have been some developments, often in the nature of an add-on, where a mainstream organisation attains project funding for an additional service. But this does not provide sustainable change, and it is diminishing for groups to be seen only ever as an 'add-on' and not be considered an automatic part, or fellow citizen, of an organisation's core activities.

Changes to commissioning and the advent of personal budgets raise important issues about whether the benefits of day care or other services can be equally, or better, met by other types of support. Unfortunately, the size of the evidence base on person-centred approaches is still too small to indicate which types of approach work best in what circumstances (Moriarty & Manthorpe 2012). If there is not yet sufficient data or outcome evidence, where's the challenge to current practice? If cuts are the currency of success, then how does this dialogue get changed?

Being mindful of difference can take different forms: through BAME projects within a generalist agency; by more sensitive and responsive generalist services which reach all communities; or by mainstreaming BAME interests in all aspects of an organisation. It is not always necessary to employ a specialist Ethnic Minority worker to do this. Every worker in an organisation can find a way to ensure that minority interests are addressed. 'Add-ons', by definition, are dependent on short-term/one-off funding. The constraints on these have become harder - it has become more costly to produce the necessary paperwork and applications, there are more restrictions on what can be delivered, and increased demands for monitoring and evaluation - all important but usually out of proportion to the scale of the operation for which funding is being sought, and the results of which are often ignored.

Ultimately it is difficult to see how much will change that will be of benefit to BAME older people in a climate where racism persists, where there are systemic contradictions in the

health and social care structures that advocate integration on the one hand, personalisation and dignity on the other, and yet provide inadequate resources to make these a reality. The mood in the BAME sector and among its older population, as reported for this study, is that they will have to do it all for themselves. Experience has consistently demonstrated a lack of progress in addressing BAME interests. Small BAME groups (as with all small groups) are struggling to keep going and should be supported and nourished because, they understand and can tackle the pressures on their communities. As the BAME older populations change and spread out in future, the balance of public and universal services is likely to change - this needs to be addressed now.

Main messages

- Little has changed for BAME older people in terms of inequality, access and unmet needs over the last 30 years.
- Institutional racism is a major contributor to the consistent lack of targeted responses to BAME older people.
- Mainstream bodies persist in not addressing the needs of minorities. BAME voluntary services are thus critical in looking after the interests of their communities.
- Small BAME groups (as with all small groups) are struggling to keep going and should be supported/nourished because, they understand and can tackle the pressures on their communities.
- Groups are providing training to enable BAME older people raise their voices, rather than waiting to be consulted or consulted in ways that don't work.
- Small amounts of money make all the difference to small groups. Accessible grants from local authorities should be available to support local activities.
- Support BAME older people to take action for themselves.

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