

Evidence Submission

May 2009



Evidence Submitted to All Party Parliamentary Group Parkinson's disease Inquiry into access to services for people with Parkinson's and their carers

Submission Outline

This response offers evidence on the impact of health inequalities on BAME communities with specific reference to the impact of Parkinson's disease. The submission draws upon ROTA's research evidence base, in particular, ROTA's consultation with London's BAME Third Sector completed in February 2009, two research projects on the provision of healthcare to BAME individuals: "Narrowing ethnic health inequalities through Local Area Agreements and other local strategies" led by the London Health Commission; and "Mental health, BAME elders and London's VCS role" carried out in partnership with Age Concern England and Age Concern London. Evidence is also used from our research and policy programme with BAME homeless individuals "Tackling Multiple Disadvantages: Linking services for BAME homeless individuals" funded by Equal. We will also be referencing anecdotal evidence collected through the work that ROTA has done with the organisations, networks and communities that it serves, and draw upon external statistical information.

ROTA would be keen to provide oral evidence if appropriate.

General Information

ROTA

Race on the Agenda (ROTA) is one of Britain's leading social policy think-tanks focusing on issues that affect Black, Asian and minority ethnic (BAME) communities. Originally set up in 1984, ROTA aims to increase the capacity of BAME organisations and strengthen the voice of BAME communities through increased civic engagement and participation in society. We achieve these aims by informing London's strategic decision-makers about the issues affecting the BAME voluntary and community sector (VCS) and the communities it serves and by making government policy more accessible to London's BAME organisations.

ROTA's policy work is evidence based in the sense that everything we do is informed by the views and real life experiences of BAME communities and the organisations that are set up to serve them. We use the term BAME to refer to all groups who are discriminated against on the grounds of their race, culture, nationality or religion. We collect this evidence through:

- Action Research (qualitative and quantitative surveys)
- The ROTA based networks of HEAR and MiNet
- Events, consultations and conferences
- Working in partnership with others

ROTA's current priority policy areas are:

- Crime and restorative justice policy and practice
- Pan-equalities and human rights policy and legislation
- Legislation and institutional changes affecting the BAME Third Sector
- Health inequalities and public services
- National and regional governance

For historical and demographic reasons, our work prioritises London, but our activities and a number of our projects have national and international significance. To this end we work in close partnership with our membership and others interested in race equality, human rights and the promotion of good relations.

Our presence in London is enhanced by our two regional networks, MiNet and HEAR.

MiNet is the London focused BAME network of networks, which joined ROTA in 2002 to strengthen the voice for London's BAME Third Sector in the development of regional policy.

HEAR is London's only pan-equalities and human rights network, which joined ROTA in January 2005. Its focus is on issues affecting London's equality and human rights third sector organisations.

BAME

ROTA uses the term BAME to refer to all groups who are discriminated against on the grounds of their race, culture, colour, nationality or religious practice. This definition includes but is not exclusive to those people of African, Asian, Caribbean, Irish, Jewish, Roma, South East Asian.

Statistical Information

BAME Populations

The 2003 Mid Year Estimates (MYE) showed that out of the 7,387,900 people living in London, at least 3 million belong to BAME groups. It is estimated that over the next ten years BAME communities will account for 80% of the increase in London's working age population (GLA London Plan 2004)

1.9 million of London's population (1,908,000) are aged 50 or over with over 1 million over state retirement age. 45% of the UK's non-white minority ethnic population lives in London including 78% of Black Africans and 61% of Black Caribbean people. (Source: Making Age Work for London). This hides huge variations across the capital with the population of Tower Hamlets in 2001 being 33% Bangladeshi, Harrow 21% Indian, Kensington and Chelsea 25% White (other than British or Irish), Southwark 16% Black African while Havering remains 92% White British (Source: Census 2001). A 1998 study of Bangladeshi elders in South Camden found 70% could not read and write English, 40% could not read and write Bengali and 65% had poor spoken English. (Living in Britain, Growing old in Britain). The percentage of BAME people in the England as a whole has increased from 9.2% in 2001 to 11.3% in 2006, and this doesn't take into account the significant number of refugee and asylum seeker individuals who represented in the work which ROTA conducts.

BAME Carers

According to a House of Common's Work and Pensions Committee Report – *Valuing and Supporting Carers* –(2007/08) 'Carers from Black, Asian and Minority Ethnic groups are at particular risk of missing out due to a lack of information. The office of the Former Mayor of London stated that 'London has 27% of Carers from BAME backgrounds and they have made clear ... that accessing information and advice are issues for them, due partly but not entirely to language differences and a need for interpretation and translation'.

BAME Elders

Older Asians are more likely to report 'not good health' and older Chinese less likely to report 'not good health' than their white counterparts (Source: Growing Old in London). For example, South Asians in London experience higher rates of Coronary Heart Disease, however "For BAME older people, their service needs are in essence no different from those of other elders, but aspects of ethnic diversity may affect the quantity and quality of service received" (Source: Health of Ethnic minority Elders in London).

BAME Communities and Parkinson's Disease

In 2004 Age Concern's BAME Elders Forum highlighted the work of the Parkinson's Disease Society who led a group of neurological organisations to improve the services and support availability for BAME individuals who were also suffering from a neurological condition. The project sought to understand the specific needs of that group and to offer guidance on how to meet these, as well as facilitate partnership working. The Society currently offer 'outreach services for black and minority ethnic communities these provide culturally appropriate information, advice and support, including some bilingual support to people in Birmingham and Leicester who have, or care for someone with, Parkinson's'. However, such specialist provision in other parts of the UK and the extent to which it is required is very limited.

KEY CONCERNS FOR BAME COMMUNITIES

1. A recent consultation that ROTA ran with London's BAME third sector identified health inequalities as a top policy priority for BAME communities. Specific areas of concern for those surveyed were unequal access to health services, the impact of poor mental health on BAME communities, and the links between poor health, social exclusion and poverty.

The vast majority of third sector activity takes place at a local level, often addressing the needs of society's most disadvantaged groups. As partners, providers and advocates, third sector organisations are ideally placed to work with local authorities to achieve results for local people - improving the quality of life and the quality of services in every area and encouraging strong and cohesive local communities. Therefore, regional governance bodies and strategic structures are increasingly relying on the third sector to help deliver on their human rights, equality, community cohesion and integration agendas. More importantly, they rely on the third sector and infrastructure organisations in particular, to provide a voice for 'hard to reach groups'. Statistics also show that the public trusts the third sector groups more than other organisations particularly in relation to equalities and human rights work. However, there is evidence to suggest that government does not engage with the third sector adequately.

Decision makers should see the third sector as a key partner for understanding and addressing health inequalities faced by BAME communities.

2. Access to services was repeatedly highlighted as a concern, especially with regards to the community cohesion agenda and the effects of social exclusion. According to those organisations consulted the extent to which local BAME services are losing funding is reducing massively the ability of BAME communities to seek support or have their needs met. Rather than work against community cohesion, specialist local services often act as a bridge between excluded communities and generic services. When this bridge is removed BAME communities who rely on them do not access generic services and their needs are left unmet. In the case of Parkinson's disease, the importance of local services has already been highlighted above. This issue, combined with specialist needs such as translation and cultural sensitive services, means that the case must be made for specialist local third sector provision to be sustained.

ROTA has witnessed a failure of culture of respect for equality and human rights in the provision of public services at large. In relation to health and social services, we identify the following issues:

- The Race Relations Amendment Act and other equality legislation are not always reflected in institutional procedures, service delivery and internal/ external policies. This is particularly relevant and timely given the forthcoming Equality Bill and the introduction of a stronger Single Equality Duty.
- Frontline staff and managers lack awareness of equality legislation.
- BAME communities have either low or no awareness at all of their entitlements under equality legislation.
- Discrimination and health inequality are not single-dimensional phenomena. Many BAME people have multiple needs and can suffer from discrimination based on more than one aspect of their identity; gender, ethnicity, age, disability, sexuality, income, family and social networks, beliefs, material circumstances, nature of migration, area of living, type and level of care needed. Many BAME people have unmet needs which affect their participation in wider society. ROTA has not witnessed yet a culture where healthcare services respond to BAME people's needs in a way that promotes independence and acknowledges their individuality.
- BAME people often face language barriers that not only prevent them from accessing written information, but also from voicing their concerns. According to Age Concern research there are currently very significant numbers of South Asian and Chinese/Vietnamese elders who face

language barriers in accessing care services. It is unrealistic to imagine that people who have reached a certain level of maturity can learn a new language.

- According to a 2003 study by the Office of the Deputy Prime Minister (ODPM), demographic difference between some population groups may have implications for managing non-discrimination in service delivery. In terms of geographical location, BAME people, gays and lesbians and some faith communities are more likely to be settled in large urban areas than elsewhere. A consequence of this is that while some large, urban authorities may have developed appropriate services for these groups, other authorities may believe that it is not necessary for them to do so as numbers are small and or/unknown (ODPM 2003).
- Some groups of BAME people of particular faiths, particularly Muslim and Sikh, need to be provided with services that take into account their religious beliefs and practices. These are not always considered important in the provision of health services.

All of the above concerns are often addressed if local services can be offered with the aim of meeting the needs of the BAME communities in their locality. Once these services are removed, many generic services will struggle to meet the same level of specialism, given the size of the organisation, the number of service users and/or the lack of awareness of specific issues affecting that community/individual.

3. It is well documented that people from BAME communities, and African Caribbean people in particular, fare worse under the mental health system. For example, a Sainsbury Centre' report describes "Circles of Fear", through which Black people, over-represented in services and typically having a negative view of the psychiatric profession, are exposed to the rough end of mental health services, yet fail to access the community, primary care and mental health promotion services that might break the cycle (SCMH, 2002, Breaking the circles of fear). The implications that this may have for people who experience depression, for example, as a sufferer of Parkinson's, or as one of their Carers, is very important. The support for improved mental health of BAME communities is crucial if they are able to take on the challenges of conditions such as Parkinson's and manage the impact that it can have on their lives. If mental health services are not improved it reduces the likelihood of BAME people seeking their support, alongside other health services when coping with an illness such as Parkinson's.

4. Poor healthcare provision should not be seen as an isolated phenomenon but as a result of a failure to mainstream a culture of equality and human rights in public authorities and beyond. Furthermore, it should not be separated from the phenomenon of institutional racism. Although, the Stephen Lawrence inquiry and the Scarman report focused on racist behaviour by the police, their conclusions and findings brought evidence to a discrimination culture that appears to exist throughout public services. In particular, Sir William Macpherson who carried out the inquiry into Stephen Lawrence's death concluded that there exists "institutional racism" across public services". Institutional racism was defined as: "The collective failure of an organisation to provide an appropriate and professional service to people because of their colour, culture or ethnic origin. It can be seen or detected in processes, attitudes and behaviour which amount to discrimination through unwitting prejudice, ignorance, thoughtlessness and racist stereotyping which disadvantages BAME people. [Racism] persists because of the failure of the organisation openly and adequately to recognise and address its existence and causes by policy, example and leadership. Without recognition and action to eliminate such racism it can prevail as part of the ethos or culture of the organisation. It is a corrosive disease" (Macpherson 1999). Ten year on from the death of Stephen Lawrence we are still faced with the challenge of institutional racism – the extent to which it impacts of agencies and organisations, as well as its impact on society as a whole.

In a 1999 study by the Department of Health, it was revealed that institutional racism exists in the healthcare system especially in relation to African-Caribbean, Asian, black African, Chinese and Mixed Heritage populations (Department of Health 1999). The same was observed for social services. In the report on black, Asian and ethnic minority older people, "They Look After Their Own, Don't They?" the Social Services Inspectorate suggested that: "In order to overcome institutional racism, Social Services Departments should re-think the approach of providing a common service for everyone and treating both black and white older people the same" (Department of Health 1998).

Given this it is crucial that we do not see the provision of health care in a silo. As BAME communities are faced with discrimination in employment, education services, the criminal justice system, housing services and social services, this will all impact negatively on their ability to navigate health service provision. For example, younger BAME generations who have experienced discrimination within the education system, may struggle to voice their needs or access appropriate health support should they experience Parkinson's in the future, or need to care for someone with this disease. Therefore, when considering how health services support and meet the needs of BAME Parkinson's sufferers and their

Carers we must also recognise the effects of wider discrimination on that service user group.

KEY CONCERNS FOR BAME ELDERS

1. BAME older people are affected by various factors that are not always relevant to the mainstream population. These include: language barriers, strong religious beliefs, strong cultural awareness, education and employment history, time of immigration, health status, family or lack of family and friends, isolation and depression. These factors leave BAME elders more easily exposed to human rights breaches by providers of public services and healthcare providers in particular.
2. BAME elders have either low or no awareness at all of their entitlements under human rights and equality legislation and are misinformed about the use and value of human rights. However, they think that values such as dignity, respect and fairness are paramount to the way they are treated by public servants
3. Many BAME elders have unmet needs which affect their participation in wider society. Many have experienced disruption in their family structures, the challenges of growing older in a country where it may not have been their intention to stay, and a lifetime of discrimination and disadvantage.
4. Although they might be victims of human rights violations, BAME elders rarely complain or even bring bad treatment to the attention of their families and the relevant authorities. This is due to a combination of factors:
 - As they rely on care provision, by definition a power imbalance is created between them and their Carers. This leads to fears of reprisals and to virtually no complaints. The comparatively small number of human rights cases brought by older people bears evidence to this claim (Human Rights Act Research Project 2002).
 - There is lack of awareness of their rights and the relevant legislation.
 - BAME elders value stoicism and feel uncomfortable “grumbling”. While with one breath they might “tell a story” of poor treatment by providers, with the next they would make excuses for them.
 - Not all BAME elders have family members with whom they can share their experiences. Therefore, they are often left alone and without a voice.

RECOMMENDATIONS

In order to address the needs of BAME communities in general, and BAME elders in particular, who may be suffering from Parkinson's disease, or caring for someone who is, there are lessons to be learnt from good practice examples. Some of the practices which, in our experience, have impacted positively or access to health and better take up of health related service include:

1. User involvement in service design – ROTA aims to involve service users in much of the research that it conducts. Recently, both work looking at services for BAME Homeless individuals and research into the impact of gangs and group offending on young people and women; have engaged directly with service users to make recommendations. The latter project was also led by service users directly throughout its first two years. Where possible services users should be involved in designing services, and on occasion delivering aspects of services, as this informs its suitability as well as support the individual.
2. Provision of language support through translation and interpretation services, especially for non-English speakers who are sometimes the most in need of basic services. For example, this has proven to prevent misdiagnosis. The difficulties with speech needs for all sufferers of Parkinson's disease have been highlighted by a number of neurological organisations. These speech challenges combined with different language needs of BAME service users increases the skills required to avoid misdiagnosis and other communication difficulties.
3. A diversity of service delivery staff which reflects the makeup of the community the health agency serves encourages BAME service users to access support, as well as potentially improving the services available.
4. Services that are culturally sensitive and appropriate are crucial for offering and sustaining support to BAME patients. The phrase 'culturally appropriate' may sound overused but it is still very relevant as evidence suggests that disregard of the subtlety of the culture of potential service users can be a barrier to uptake of services, which further exacerbate health inequalities.
5. Beliefs and values are equally important to people from black, Asian and ethnic minority communities. Things that are as basic as lack of understanding of the dietary needs and habits and religious beliefs and practices of ethnic minority service users do often act as barriers to access.
6. Some research evidence suggests that segments of BAME communities are losing faith in generic health service provision because they sometimes do not provide what these communities want. Community-based services which are more accessible are now increasingly seen as a viable option for better quality service.
7. A recognition of multiple-disadvantage and the implications that this may have for BAME patients. For example an elderly BAME, female, Muslim Parkinson's sufferer has the potential to be discriminated against on the grounds of race, gender, age and faith, individually as well as when they

all intersect. Not enough is known about the impact of such intersectionality but it is crucial is responding with a service considers potential barriers to meeting patient need.

8. Support for BAME families, as well as BAME patients, is imperative if one is to also consider the role of Carer/s. The impact of wider discrimination that an a Carer my face, for example in education or employment, and how this affects the ability of a Carer to offer support to a patient and to cope themselves will determine to what extent services can be accessed and maximised on the ground.

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targeting social policy

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