

**PRIAE** Policy Research Institute on Ageing & Ethnicity

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PRIAE POLICY RESPONSE  
to the Call for Evidence -  
'Mayor of London's  
Health Inequalities Strategy'

Submitted to the  
Greater London Authority

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## PRIAE Response to the Call for Evidence - 'Mayor of London's Health Inequalities Strategy'

### Section 1 Introduction

PRIAE is the leading organisation specialising in ageing and ethnicity in the UK and across Europe. Established as an independent charitable institute in 1998, PRIAE seeks to improve health, social care, housing, income and pensions, employment and quality of life for current and future generations of black and minority ethnic (BME) elders at the national and European level. PRIAE provides that important intersection between age and ethnicity working with multiple discrimination and inequalities and across all ethnic minority groups in London. Given this unique specialisation, Mayor's building of strategy on health inequalities where its ethnic minority population is ageing – and rapidly- presents an important opportunity for the Mayor to refer and to use PRIAE's nine years of ground breaking work. Although PRIAE is not based in London it has always had a London specific approach to its work starting from its commissioned report to the Royal Commission on Long Term Care for the Elderly to the Europe's largest research in health of BME elders which PRIAE created and led called the 'MEC Minority Elderly Care' Project where London was one of the three research sites. The focus of PRIAE's work in London is deliberate: due to the city being largest for BME elder population who experience considerable

health inequalities and the population growth rate in the current and next two decades with increasing need. Added to this is the establishment of many BME age organisations to which PRIAE provides a national 'umbrella' structure. Discussion of the needs of BME elders cannot be undertaken without reference to the BME voluntary organisations based in these communities. They play a critical role in supporting BME elders. PRIAE works with them in specific ways in policy, information & research and service developments. (Further information about PRIAE is detailed at the end of this document.)

Sources of information drawn upon for this submission: This response draws primarily on the considerable body of evidence PRIAE has produced on the health and social care needs of BME elders since it was established in 1998. We begin with the recently launched Minority Ethnic Elders' Policy Network (ME<sup>2</sup>PN) which is developing an information and engagement link between BME elders, BME voluntary organisations, mainstream age organisations and policymakers. ME<sup>2</sup>PN aims to increase confidence and capacity of BME elders and age organisations and lead to the development of 'BME elder sensitive' policy making. The GLA could utilise this unique mechanism for pursuing further this consultation to affect better implementation. For example ME<sup>2</sup>PN recently held a London conference for BME elders and BME age organisation managers at the Central Hall, Westminster on 7<sup>th</sup> February 2007. Apart from key note speeches in health and very enthusiastic participation of some 120 BME elders (from some 20 ethnic- sub ethnic backgrounds), workshops on Active Ageing with Mental Health and Palliative Care were held at the London conference at

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<sup>12</sup> France, Germany, the Netherlands, Spain, Finland, Hungary, Bosnia-Herzegovina, Croatia, Switzerland and the UK

Central Hall Westminster on Wednesday. Evidence provided by BME elders in these workshops is utilised in this response.

PRIAE has conducted seminars with BME elders in London in 1998 for its report to the Royal Commission on Long-Term Care for the Elderly (1999), for its 2002-2005 Minority Elderly Care (MEC) project, which covered 10 European countries and, supported by the European Commission (EC) under its Fifth Framework Research Programme, was awarded the highest research rating in its stream and remains the first and only research project to be supported in ageing and ethnicity in the EC's 24 years of Framework funding. Here London's BME elders experienced at first hand a major quantitative research enterprise and its results. The MEC research with London as one of its sites conducted face to face interviews with over 100 BME elders in their chosen language, over 20 BME elder organisations and some 100 health and social care professionals. Other work included covers dementia and PRIAE's work in association with with Help the Aged Dignity on the Ward (2001). Through this and other experience of engagement with BME elders in London, PRIAE has amassed a unique and considerable body of evidence which can help to inform the Mayor of London's Health Inequalities Strategy. Our work is particularly effective because of the comparative approach we have employed between London and other parts of the UK (particularly West Yorkshire and Scotland), and between the UK and other European countries, helping to situate evidence in context.

In submitting this response, our aim is to draw attention to the particular BME elders' experience of health inequalities as well as their response to it and to suggest ways of addressing disadvantage associated to a large extent with current socio-economic trends. The average weekly income of an ethnic minority

male is 32.5 per cent less than his white counterpart between the ages of 60 to 64, a difference that increases to 44.7 per cent over 65. One in six low-income households where adults are in work is headed by a member of an ethnic minority. Our evidence therefore focuses solely on women and men from BME communities. We do however recognise that these concerns are also of relevance to other disadvantaged groups where inequalities also persist. During this response, unless otherwise stated, the examples mentioned and recommendations refer to policy in the UK and we focus on evidence obtained through research and engagement in London.

A note on Terminology: At PRIAE we use in most cases the term 'black and minority ethnic elders (BME elders)' to refer to those who have worked, lived, aged and are ageing in London as a result of colonial connection and/or refugee background; as a result of economic migration within the European Union and being a long established national minority.

## Section 2: Executive Summary of recommendations

RECOMMENDATION 1: Efforts to tack health inequalities must respond to differences by age, ethnicity, gender, disability and religion and their specific connections/interactions.

RECOMMENDATION 2: Effective information is needed to encourage take-up of services by BME elders

RECOMMENDATION 3: Action needs to be taken to ensure that BME elders are given appropriate primary care services. Particularly issues that need to be addressed are language and communication difficulties, and promoting better cross-cultural understanding as well as rights to services.

RECOMMENDATION 4: Address the low take-up of community health services by BME elders **through involvement and engagement of BME Elders and Organisation**

RECOMMENDATION 5: In relation to social care services, action needs to be taken to ensure that BME elders receive appropriate social care, and the GLA should undertake an assessment of whether supply of social care services is currently meeting demand, and will continue to do so, and put in place a strategy to address any problems identified

RECOMMENDATION 6: Use the following expectations told to PRIAE by BME elders as a check-list for good practice:

- being treated with respect
- feeling safe and comfortable

- having dignity respected
- that professionals behave with integrity (re: MEC research)

RECOMMENDATION 7: Promote clear and strong policies in health and social care organisations on race and equality and provide training and education for staff in cultural competence

RECOMMENDATION 8: Sources of information on health and social care services need to be culturally appropriate. Each organisation needs to have a clear policy regarding the provision of interpretation, translation, **engagement and** advocacy. Appropriate media and settings should be used to disseminate information. Health and social care organisations should work closely with BME voluntary organisations

RECOMMENDATION 9: Given the particular socio-economic circumstances of many BME elders, there should not be complicated procedures or means-testing in order to get support

RECOMMENDATION 10: There needs to be greater support for BME elder care centres in order that all sections of the community can be reached

RECOMMENDATION 11: PRIAE has made a series of recommendations on

- hospital care
- mental health services
- active ageing
- palliative care
- heart disease and diabetes

which are presented in this response. These recommendations constitute a handbook of good practice which could (and we hope shall be) used by the GLA in its Health Inequalities Strategy.

This response also includes messages from BME elders in London told to PRIAE at its recent Minority Ethnic Elders' Policy Network (ME<sup>2</sup>PN) conference POLICY and PRACTICE in AGEING on Wednesday 7<sup>th</sup> February 2007. These concerns from BME elders in London, and examples of good practice and recommendations, should now be utilised by the GLA in its Health Inequalities Strategy.

PRIAE would be interested to work with the GLA further to develop and implement the Mayor of London's Health Inequalities Strategy, and future work to address minority needs in old age.

### Section 3: Background information

Any response to the demographic shift in the UK must take sufficient account of the experiences of BME elders who have largely arrived in the UK as migrants.

More detailed information about the socio-economic position of BME elders in the UK is provided below.

#### Mayor of London's Health Inequalities Strategy – background information

The Government's Greater London Authority (GLA) Bill, announced in July 2006, proposes to give new health responsibilities to the Mayor in addition to his existing duty to promote health.

These will include a duty to work to reduce health inequalities. The Mayor will be required to develop and lead a London-wide health inequalities strategy, working with the GLA Health Advisory in the Department of Health, the London Strategic Health Authority and other partners.

The GLA Bill also seeks to:

- Strengthen current partnership arrangements and strategic leadership to improve health and reduce health inequalities in London
- Improve the use of Health Impact Assessments to test how strategies, projects and initiatives impact upon public health and health inequalities
- Ensure ongoing joint strategic work between the Mayor, the Regional Director of Public Health, London's NHS, and the London Assembly.

The Mayor of London's Health Inequalities Strategy aims to:

- Be specific to London and fully reflect London's diversity
- Focus on outcomes and identify who should lead on action in different areas
- Focus on the broad determinants of health
- Be evidence-base, including appropriate use of community intelligence and stakeholder experience as well as traditional data sources and published research
- Strengthen existing and planned GLA strategies and programmes
- Build on regional, national and international experience of effective strategic partnership work on health inequalities.

This Call for Evidence is looking for information about respondents' community's experience, or their views, about:

1. The things that affect their health and well-being
2. Health and related services
3. The interventions that work

The Greater London Authority has acknowledged that there are particular gaps which they would value evidence about, including:

- Health determinants and health outcomes for Black, Asian and minority ethnic communities, disabled people and other excluded groups
- The effectiveness of action that engages specific socio-economic, ethnic or vulnerable groups in the following areas:
  - tackling unemployment and promoting access to work
  - mental health promotion
  - encouraging physical activity and healthy eating

- promoting sexual health and preventing unplanned teenage pregnancy
- dealing with specific health problems such as obesity, alcohol misuse or long-term illness.

### Structure of this response

This response provides the categories of information requested in this Call for Evidence and structures this information by:

- Evidence from PRIAE on health inequalities and key issues
- Recommendations by PRIAE

The evidence covers both physical and mental health, health and social care services.

## Section 4: Evidence from PRIAE on health inequalities and key issues

### Health outcomes

Older people from minority ethnic groups are more likely to describe their health status as poor than the total population (PRIAE MEC research 2006; Age Concern, 2002: 3).

PRIAE has in particular drawn attention to the problem of diabetes and coronary heart disease in BME communities through the 'What Works For Us' project, funded by the Department of Health (R& D division).

PRIAE's joint report with National Council for Palliative Care (NCPC) provides the following overview of evidence on health inequalities and BME elder issues:

- There are higher rates of coronary heart disease amongst Pakistani and Bangladeshi groups and higher levels of hypertension in the Black-Caribbean group.
- Mortality rates associated with diabetes are higher for South Asian and the Black-Caribbean group and end stage renal failure is significantly higher among South Asian people with diabetes, compared to White, British diabetics.
- In general, elders from minority ethnic groups are more likely to report being in poor health and that activity in their daily lives has been restricted due to illness or injury.
- The most prevalent life-limiting diseases amongst elders from Black-Caribbean, South Asian and Chinese and Vietnamese backgrounds are coronary heart disease and cardiovascular

conditions, with other chronic and co-existing conditions being diabetes, arthritis/rheumatism, lung/breathing problems, osteoporosis and kidney problems.

- There is an excess of deaths from cerebro-vascular accident (stroke) amongst Black-Caribbean elders; high rates of coronary heart disease amongst elders from South Asian backgrounds; and high rates of diabetes amongst elders from the Caribbean, Africa, Asia and the Middle East (Gunaratnam, 2006)

Additional significant health inequalities to note are

- The Health Survey of England (1999) reports that South Asian men and women as well as all Black Caribbean women aged 55+ report relatively high levels of limiting longstanding illness compared to the general population (Patel, 2003: 21).
- The Health Survey of England (1999) also reports that Black Caribbean men and all BME women aged 55+ have a greater incidence of high blood pressure than the general population (Patel, 2003: 23).
- Among men aged 55+, Indians and Pakistanis consult their GP on mental health matters almost twice as often as the general population. South Asian and Black-Caribbean women aged 55+ have higher rates of consultation than the general population. This is particularly true of Pakistani women aged 55+. No national data exist on the prevalence of dementia among the BME population (Patel, 2003: 23).

In 2005 PRIAE completed its Minority Elderly Care (MEC) research project, a three-year project covering 10 European countries<sup>2</sup>, 26 ethnic minority backgrounds, 901 health and social care professionals, 312 voluntary organisations and which employed 30 or more researchers.

MEC was supported by the European Commission (EC) under its Fifth Framework Research Programme. The MEC proposal was awarded the highest research rating in its stream and remains the first and only research project to be supported in ageing and ethnicity in the EC's 24 years of Framework funding.

In the UK, 390 face-to-face interviews were conducted with BME elders from three different ethnic communities<sup>3</sup>, 101 health and social care workers were interviewed using a face-to-face, structured questionnaire, and representatives from 50 BME voluntary organisations were interviewed in total. The interviews were conducted in London, West Yorkshire and Scotland.

MEC UK (2005a) findings highlight a number of health inequalities relating to BME elders and also that there are a number of differences by ethnic group, gender, age, and location. We briefly state these as:

#### Health inequalities by ethnic group

- African-Caribbean elders had a higher incidence of high blood pressure than South Asians who, in turn, had a higher incidence than the Chinese/Vietnamese elders.
- African-Caribbean and South Asian elders had a higher incidence of diabetes than the Chinese/Vietnamese.
- Heart disease and lung/breathing conditions were highest amongst the South Asians.
- Osteoporosis and memory problems were highest amongst the Chinese/Vietnamese.

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<sup>3</sup> African-Caribbean, South Asian, Chinese/Vietnamese

### Health inequalities by gender

- Men had a higher incidence of diabetes compared to women (men 42%, women 26%). Women had higher incidences of arthritis/rheumatism, musculoskeletal disorders, osteoporosis and constant headaches/migraine. The differences between men and women with regard to muscle and bone disorders are quite marked: arthritis and rheumatism – women 63%, men 46%; osteoporosis – women 17%, men 8%; musculoskeletal disorders – women 46%, men 29%.
- More women had physical problems and more men had emotional problems. There were slightly more men than women with no problems at all.

### Health inequalities by age

- The serious health problems were not related to age. The age-related conditions were problems with eyesight, high blood pressure, hypertension, dental problems, sleeping problems, hearing problems and kidney/urinary tract disorders.
- The Chinese/Vietnamese had a lower score than the other two groups on the index of physical limitation. This index was related to age, with the measure rising across all age groups. The South Asians had a lower score than the other two groups on the index of well-being. There were no differences in this measure by region, gender or age. The African-Caribbeans had a higher score than the other two groups on the index of self-esteem. Those aged 64 years or below had a higher score than the older age groups.

### Health inequalities by region

- There were only a few regional differences. Scotland had a higher incidence of dental problems and thyroid disorders.

Yorkshire had a lower incidence than the other two regions of musculoskeletal disorders, kidney/urinary tract disorders and mental problems.

Given this lack of regional differences in health inequalities, PRIAE would argue that the GLA needs to consider the evidence presented in this response in its entirety. Services must be responsive to local needs and infrastructure however. PRIAE has offered GLA this unique London specific MEC research results for its use with scope for further analysis. We await a response.

**RECOMMENDATION:** Efforts to tack health inequalities must respond to differences by age, ethnicity, gender, disability and religion

### Accessing services

Age concern argues that difficulty accessing or even being refused services reflects a lack of cultural sensitivity (Age Concern, 2002: 4).

Information is also a key dimension affecting take-up of services, as PRIAE found when engaging BME elders and BME age organisation managers for its report to the Royal Commission on Long-Term Care for the Elderly:

“The delegates spoke cogently about why in the 1990s it was so difficult to establish what was available, where and how to access basic information on services. Research studies which we have cited all point to lack of knowledge and information on social care, primary and secondary health services (‘going beyond visits to the

GP and the hospital') among BEM [black and ethnic minority] elders and carers" (PRIAE, 1999a: 259).

PRIAE found in its MEC UK research study that Social Services were more likely than NHS respondents to agree that BME elders have specific problems of access; and managers/planners were more likely than professionals to agree that BME elders have special access problems. The top reasons given for the particular circumstances of BME elders were language problems, clients' cultural norms and values, and the experience of discrimination (PRIAE, 2005a).

**RECOMMENDATION:** Effective information is needed to inform and encourage take-up of services by BME elders

### Primary care

In PRIAE's 1999 report for the Ethnic Minorities Steering Group at Age Concern as part of the Millennium Debate of the Age, Ageing Matters Ethnic Concerns, PRIAE reported that:

"Some...studies show evidence for a relatively high frequency of using health services, including general practitioners (GP's) by elderly Afro-Caribbean and Asians compared to White groups. However, frequency of contact with GP's and hospitals does not necessarily reflect the quality of treatment received" (PRIAE, 1999b: 44-45).

It is now well accepted that while "black and minority ethnic populations are the highest users of primary care services, they are least likely to gain access to appropriate health services and treatment" (Age Concern, 2002: 3).

PRIAE's MEC research and other work shows that language and communication problems, or cultural differences explain part of the problem; the other is the complexity of the system; providers not being responsive to different needs agenda and professionals' responses to BME elders. Discrimination was cited by professionals in the research as a major concern also.

Through PRIAE's MEC UK (PRIAE, 2005a) study we have been able to refine our understanding of how primary care services are used by different ethnic groups, levels of satisfaction, and associated consequences:

- High proportions of informants used GP services, dentists, opticians and also more than half the informants had used the hospital outpatient clinic. Overall, satisfaction levels with the different services were high with all mean scores being over the value of 3.
- The Chinese/Vietnamese elders used the GP service less than the two other groups. The frequent users of GP services had a poorer standard of general health, a poorer quality of life and enjoyed life less. They needed more medical treatment to function every day and during the last month had more pain which interfered with their normal work or regular activities. They had more physical limitations and scored lower on the indices of self-esteem and well-being.
- The South Asian elders were less satisfied than the African-Caribbeans with GP services. A high proportion of Chinese/Vietnamese elders (64%) expressed themselves 'somewhat' satisfied with their GP service.
- Those less satisfied with their GP service had poorer general health, a poorer quality of life and enjoyed life less compared

to the more satisfied users. There was no difference in how much medical treatment the less satisfied or the more satisfied needed to function, but those who were less satisfied suffered more interference with their daily activities from pain and had a higher score on the index of physical limitations. They also scored lower on the indices of self-esteem and well-being.

**RECOMMENDATION:** Action needs to be taken to ensure that BME elders are given appropriate primary care services. Particularly issues that need to be addressed are language and communication difficulties, and promoting better cross-cultural understanding

### Community health services

Although many older people from black and minority ethnic groups are registered to and use General Practitioner services, the usage of community health services among black and minority ethnic elders tends to be low (Age Concern, 2002: 3).

**RECOMMENDATION:** Address the low take-up of community health services by BME elders

### Social care

Older people from black and minority ethnic communities do not always receive appropriate social care. Reasons include language barriers; insufficient knowledge of availability and rights to social and public services; lack of awareness of social rights; low expectations of their life in the UK; negative experiences of retirement; poor mental and physical health; racism – overt and

often inadequate – at individual and institutional levels, including professional assumptions that their family will provide care and a ‘colour-blind’ approach to service provision and assessment; inadequate support from their family; lack of consultation with black and minority ethnic communities in service planning and delivery; geographical isolation, social exclusion and poor outreach (Age Concern, 2002: 4; Age Concern, 2003: 19).

A survey of social services departments’ and district health authorities’ provision of services for black and minority ethnic elders found that there was great variation between organisations in the extent to which they catered for any specific needs of minority ethnic elders. What provision did exist was patchy and small-scale. The main reasons given by staff for lack of provision were: lack of resources; lack of demand/small numbers; lack of organisational commitment; lack of initiative by black or minority ethnic populations themselves; racism; ageism (Age Concern, 2002).

PRIAE’s MEC UK findings provide primary evidence on social care service usage patterns of BME elders, levels of satisfaction, and health outcomes show:

#### Service usage

- The services with the highest proportion of users were the social day-care services and the transport services (the use of these two services could be linked). Excluding the residential services, those services which were regularly used (i.e. daily or once or twice a week) are home care, social day-care and transport services.
- The African-Caribbeans had a higher incidence of usage of social day-care services than the other two groups. The African-Caribbean elders were also more likely to use the

services daily or once/twice per week than the other two groups.

#### Levels of satisfaction

- Overall, satisfaction with social care services was high. The South Asians were less satisfied with home nursing, home care and day care. The older informants (75 and over) were less satisfied with day care than younger informants. There were no differences in satisfaction levels with regard to gender, but there were some regional differences.

#### Health outcomes

- We compared the 'frequent users' of day-care with the 'less frequent users'. The frequent users had better general health, enjoyed life more, needed less medical treatment, had less pain interfering with daily activities, and scored higher on the index of self-esteem and index of well-being than the 'less frequent users'. There were no differences between the groups with regard to their (self-assessed) quality of life, the availability of help when needed/wanted and the index of physical limitations.

#### Social care provision

- PRIAE is concerned that the number of residential care beds has been steadily reducing since 1995. Age Concern asserts that even with possible expansion of alternatives such as extra care sheltered housing [discussed in subsequent chapter], demand for residential beds is likely to grow, meaning that the availability of residential care beds will not be able to meet demand (Age Concern, 2006: 54).

RECOMMENDATION: In relation to social care services, action needs to be taken to ensure that BME elders receive appropriate social care, and the GLA should undertake an assessment of whether supply of social care services is currently meeting demand, and will continue to do so, and put in place a strategy to address any problems identified

## Palliative care

Palliative care services are used mainly by people with cancer. Cancer mortality is relatively lower in most minority ethnic groups. However, emerging research from the USA suggests that there are ethnic disparities in clinical outcomes for cancer patients and that those from minority ethnic groups can have worse survival rates. Minority ethnic elders can also be more likely than White patients to receive inadequate cancer pain control (Gunaratnam, 2006: 4).

Deaths from all types of cancer are high in Irish people in the UK and most are in excess of all other groups (Age Concern, 2003: 11).

It must also be noted that particular ethnic groups are at greater risk of contracting particular types of cancer (e.g. cancer of the liver) and therefore the general pattern noted above must not divert attention away from more concentrated work on BME elders and rates of cancer.

Despite relatively high levels of satisfaction with health and social care services (PRIAE, 2005), there is some evidence to suggest poorer access to palliative care services for minority ethnic elders. Wider studies show that access to services for minority ethnic groups can be limited, particularly by the 'gate-keeping' of GPs (Gunaratnam, 2006: 5).

## Recommendations by PRIAE

What do BME elders want from health and social care?

PRIAE's MEC UK research found that the highest expectations from BME elders related to:

- being treated with respect
- feeling safe and comfortable
- having dignity respected
- that professionals behave with integrity

It is encouraging to see a clear drive in current policymaking towards promoting dignity in care. PRIAE would argue that the above four expectations should be used by policymakers as a checklist for effective policy making.

RECOMMENDATION: Use the following expectations told to PRIAE by BME elders as a check-list for good practice:

- being treated with respect
- feeling safe and comfortable
- having dignity respected
- that professionals behave with integrity

Cultural awareness, discrimination and institutional racism

The Royal Commission on Long Term Care for the Elderly (1999) used PRIAE recommendation for its main report: “‘It should be a priority for Government to improve cultural awareness in services offered to black and minority ethnic elders,’ said the Royal Commission in its recommendations to the Government (1999). We would add to this, the implications of the recommendations from the Macpherson Report and the recognition given to institutional racism. This necessitates effective antiracist strategies and programmes in all aspects of services and specifically in research, development, communication and training” (PRIAE, 1999b: 13).

This evidence relating to institutional racism stems from PRIAE’s 1998 seminars for the Royal Commission on Long-Term Care for the Elderly:

“Given this continuity of mainstream neglect and/or indifference, we can state that this constitutes de facto racism. In other words, the mainstream services by default are structuring the segmentation of care to minority ethnic elders into a long-term solution” (PRIAE, 1999a: 258).

Mainstream health, housing and social care organisations need to urgently examine (and consequently act upon) on why they continuously appear to have difficulties in effectively responding to BEM elders and their carers’ ordinary not special, needs. If they continue with the present approach of ‘ad hoc, patchy and piecemeal developments’, they will by default, have structured BEM elder centres into segmented long-term care solution on marginal resources, endorsing de facto racism in a modern society as we approach the 21<sup>st</sup> century. BEM elders’ settlement in concentrated areas presents planners with less difficulty in implementing the proposals (PRIAE, 1999a: 259).

Examples of basic cultural requirements not currently being met are summarised in the following statement, and constitute specific recommendations policymakers can use to evaluate services:

“All the major studies we examined in the 1980’s, in the 1990’s and EMSG’s comments point to a consistent and clear pattern in needs being expressed: that care must be appropriate, accessible and adequate. So requiring a particular type of food, being able to exercise religious and spiritual practices, day care in appropriate locations and available for more than a day, having staff who can understand and communicate appropriately, being able to live with dignity in a nursing, residential, and sheltered housing without having to face racial abuse from residents or staff, being able to wash in privacy and so on – are not special requirements. They are not even choices. They are basic ordinary needs for daily living, which we probably take for granted” (PRIAE, 1999b: 45-46).

Of the 101 health and social professionals interviewed for PRIAE’s MEC UK study, 77 had witnessed racism at some time from health or social care professionals towards users, and 87 had witnessed racism on the part of other service users. BME respondents were more likely than White European informants to say that they had observed racism on the part of health and social care professionals. 78 stated that measures were being, or had been, implemented to counter racism; a further 9 said that measures were planned.

Having and implementing clear, strong policies on race and equality is essential for every health and social care organisation and this should be supported by training and education in cultural competence. Together, these should provide very practical guidance on how fully and properly to serve patients/clients from

very diverse backgrounds. Neither discrimination in provision, nor racism from patients to staff and/or other services users should be tolerated (PRIAE, 2005a).

The BME voluntary organisations interviewed by PRIAE as part of the MEC UK study also agreed:

“It is essential that all frontline service-delivery staff have training in the delivery of multicultural/intercultural services” (PRIAE, 2005a: 17).

Although some of the above evidence is now nearly 10 years old, these points are as pertinent today as when they were first made.

In March 2006 for example, the Commission for Social Care Inspection (CSCI), Audit Commission and Healthcare Commission reported that:

“During our inspections of local communities, we also found that awareness of diversity issues was at an early stage of development, with more work required to ensure that older people from black and minority ethnic groups receive services that are culturally sensitive and responsive to their needs” (CSCI et al., 2006: 10).

**RECOMMENDATION:** Promote clear and strong policies in health and social care organisations on race and equality and provide training and education for staff in cultural competence

Accessing services

The actions suggested above and below in relation to increasing cultural awareness and improving information and communication are central in the strategy for making it easier for BME elders to access health and social care services.

Based upon findings relating to Chinese/Vietnamese elders in PRIAE's MEC UK research, we have also made the following specific recommendation for future investigation:

"The Chinese/Vietnamese elders used various health services (GP, district nurse, hospital outpatients) and some social services (social day care in hospital, home care) considerably less frequently than the other two groups. The results show that this was not entirely due to the Chinese/Vietnamese having better health. We suggest that there are two other possible reasons: (i) they have more reliance and trust in traditional Chinese medicine or (ii) they are worried about using UK GP services for some reason, for example, they may not be aware that services in the UK are free and open to everyone who needs them. Outreach work should be undertaken with the Chinese/Vietnamese community to ascertain the precise reasons for the lower use of services and efforts should be made to redress any problems. Furthermore, greater acceptance of proven alternative therapies within mainstream provision should be promoted" (PRIAE, 2005a).

## Information and communication

In PRIAE's MEC UK study, many of the biggest gaps between expectations and perceptions had to do with information and communication, which clearly suggests that there is an information gap in services provision. This is a long standing issue since the area of BME elders' came into focus in the 1980's. What PRIAE's

MEC research shows through its rigorous statistical analysis is that progress in this area is slow and that a basic requirement to engage with any intervention is the necessity for good quality information. There are numerous things which can be done about this, for example: increased outreach and community based work (and in some areas like Camden, Brent, Newham or Wandsworth with its multilingual services and hospital based outreach minority ethnic staff access can be better facilitated); better liaison with BME voluntary organisations and use of social care institutions to provide information to users about other services and institutions better use of the Internet as a patient source of information; hospital radio in minority languages; .

Many organisations do provide translation or interpreter services and these must be considered important and essential.

Furthermore, organisations should have a clear policy regarding provision of translation/interpretation services and the role of multi-lingual staff in providing a means of communication with patients/clients. Such a policy needs to be clearly communicated to BME communities (PRIAE, 2005a).

The 'hush-hush' system to information on services needs to now be vocalised with a planned strategy in marketing of services. Here good quality translated leaflets are only one part of the communication programme (PRIAE, 1999a: 259).

**RECOMMENDATION:** Sources of information on health and social care services need to be culturally appropriate. Each organisation needs to have a clear policy regarding the provision of interpretation, translation and advocacy. Appropriate media and settings should be used to disseminate information. Health and

social care organisations should work closely with BME voluntary organisations

### Paying for care

Assessment of an elderly person in respect to health and/or social care should take into account the individual's overall quality of life and general living conditions (PRIAE, 2005a).

Many elders are living on low incomes and, in these circumstances, the option to pay for care does not exist. While most health services in the UK are free, some social care services do have charges, although these may be waived in certain situations. It is important that any system of charging is easy to understand and that the elder's entitlement to free services is properly explained. There should not be complicated procedures or means-testing in order to get support (PRIAE, 2005a).

**RECOMMENDATION:** Given the particular socio-economic circumstances of many BME elders, there should not be complicated procedures or means-testing in order to get support

Given the close and pervasive relationship between socio-economic conditions and health outcomes, a key dynamic in the persistence of health inequalities, the Health Inequalities Strategy must be part of a broader strategy to promote employment opportunities for individuals from black and minority ethnic communities, and tackle income disparities. PRIAE recently launched its Summary of Results from the CEMESME Contribution of Ethnic Minority Employees to Small and Medium Sized Enterprises (SMEs) Research Study (PRIAE, 2007), which could help to inform this aspect of the GLA's strategy.

## The role of BME voluntary organisations

The UK has had a thriving and proactive voluntary sector in the BME community since the early 1980s. Some are well-established institutions within UK society; a majority are micro-organisations which struggle to survive from one year to the next. Their primary focus is to serve BME elders and many are ethnically based given their specific origin in the absence of mainstream care – faith is not the main focus – though that is used to provide a culturally relevant service; they also provide essential social and community care to a large proportion of the BME population. In respect of social care they represent an alternative service provider to the mainstream for BME elders (PRIAE, 2005a: 14).

In the 1980s Naina Patel analysed empirical studies and reached several conclusions, one of which concerned the centrality of BME organisations in the supply of care. Assessing the evidence, such organisations were acting as 'primary providers' (substituting mainstream services) rather than acting as 'complementary providers' to mainstream health, social and housing services (Patel, 1990).

BEM elder care centres should therefore be strengthened, expanded to meet growing demands and regarded as primary providers of care rather than as an alternative to the mainstream.

Commissioning and Funding bodies need to seriously examine their knowledge base and act in a non-stereotypical way in support of this (PRIAE, 1999a: 259).

Our concern here is not that the location of services are in BEM elder care centres. Rather that such location tends to be

inadequately supported, maintained and expanded. This makes the development of comprehensive services and an ability to reach all sections of BEM elders (disabled, frail for example) problematic (PRIAE, 1999a: 258).

It is important to emphasise that, despite the importance we place on the role of BME voluntary organisations, which should as a priority be supported, our concern is not that the location of services be in BME elder care centres as a matter of principle: BME elders, after all, are part of this society and hence entitled to mainstream services (Patel, 1990: 58).

**RECOMMENDATION:** There needs to be greater support for BME elder care centres in order that all sections of the community can be reached

### Hospital care and dignity in care

PRIAE has found that the services with the lowest level of satisfaction amongst BME elders were hospital accident and emergency, and rehabilitation (PRIAE, 2005a).

In 2000 between October and November PRIAE interviewed 32 elders from three ethnic groups (African-Caribbean, Asian and Chinese, with a number of them sharing sub-ethnicity, language, religion and social class) in England and Scotland for a joint report with Help the Aged Dignity on the Ward (2001).

The elders were aged 55-80 years and over. Twenty were women, twelve were men, and they came from East Scotland, Leeds and three London Boroughs.

PRIAE reports that the changes elders would make are:

- The availability of interpreters on the ward
- To be kept informed about their medical status and to be actively involved in any decisions about their care
- More nursing staff from ethnic minorities
- Nursing staff who have a sensitive approach and are aware of racial and cultural needs
- Measures to tackle rudeness and insensitive attitudes on the part of hospital staff
- Radical improvements in the type, quality and quantity of food
- Menus could be illustrated to overcome language difficulties
- To have religious needs met
- Care tailored to the individual's needs
- Better staffing levels
- Privacy and confidentiality on the ward
- Separate male/female wards
- Improved shower/washing facilities

PRIAE continues to support the above as recommendations.

Despite recent policy statements on the importance of dignity in care, considerable work still needs to be done. In March 2006 the Commission for Social Care Inspection (CSCI), Audit Commission and Healthcare Commission reported that:

“some older people experienced poor standards of care on general hospital wards, including poorly managed discharges from hospitals, being repeatedly moved from one ward to another for non-clinical reasons, being cared for in mixed-sex bays or wards and having their meals taken away before they could eat them due to a lack of support at meal times. All users of health and social care services

need to be treated with dignity and respect. However, some older people can be particularly vulnerable and it is essential that extra attention is given to making sure that givers of care treat them with dignity at all time and in all situations. To fail to do this is an infringement of their human rights” (CSCI et al., 2006: 9).

## Carers

Carers’ informal care should be recognised in monetary terms for the care they provide. They should be further supported in information, personal and skills development including financial planning, to aid greater economic independence in their own old age (PRIAE, 1999a/1999b).

## Mental health

In March 2006, the Commission for Social Care Inspection (CSCI), Audit Commission and Healthcare Commission published Living well in later life: A review of progress against the National Service Framework for Older People<sup>4</sup>.

The Living well in later life report states that explicit age discrimination has declined since the National Service Framework (NSF) was published as a result of NHS trust auditing policies on access to services and social services reviewing their eligibility criteria.

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<sup>4</sup> The Commissions inspected 40 NHS Trusts and 10 local authorities in England. They focused on five themes that cross-cut the eight standards in NSF: tackling ageism and promoting equality; involving older people; designing and delivering services around older people; living well in later life; and leading organisations through change; and the three conditions included in NSF: stroke, falls and mental health

The exception to this decline however is said to be mental health services where the organisational division between mental health services for adults of working age and older people has resulted in the development of an unfair system, as the range of services available differs for each of these groups. For example, out-of-hours services for psychiatric advice and crisis management for older people are not as developed as those for adults of working age. Older people who have made the transition between these services when they reached 65 have said that there were noticeable differences in the quality and range of services available (CSCI et al., 2006: 8).

PRIAE produced a ground-breaking study in 1998 detailing measures to improve provision to ethnic minority people suffering from dementia. This work brought together researchers from the UK, Denmark and France who produced a series of recommendations for good practice (Patel, N. and Mirza, N. et al., 1998).

The study was followed by an innovative video in 1999, *Dementia Matters Ethnic Concerns*, which sought to continue informing mainstream and statutory providers of the needs of ethnic minority older people suffering from dementia.

The key recommendations from the CNEOPSA (Care Needs of Ethnic Older People Suffering from Alzheimer's) project are:

- Targeted developments and research must be put in place to assist ethnic minorities in accessing dementia care, as this has been so impoverished in the past. The involvement of mainstream statutory and voluntary providers is crucial due to the resource limitations of the dementia sector as a whole.

- An information and communication strategy needs to be put in place to increase awareness of dementia and support for carers. A number of cultural barriers continue to prevent ethnic minority groups from recognising the onset of Alzheimer's or seeking outside help.
- A training package needs to be put in place for health and social care professionals, allowing them to engage with the issues and develop their own appropriate strategies. PRIAE has begun running such sessions, and the support we have received indicates a willingness of health care professionals to participate.
- Mainstream organisations need to employ specialist minority ethnic workers, who are well placed to ascertain needs and anticipate problems. This would also help to stimulate appropriate care developments for the future.
- Policymakers need to recognise that minority ethnic organisations are essentially acting as primary providers of care in the absence of mainstream services. This should be reflected in future funding arrangements, as they currently suffer from scarce and short-term resources.

### Active ageing

PRIAE has expressed support for the creation of an Active Ageing Unit (PRIAE, 1999b: 33) and maintains that:

“active ageing as part of age as a resource is healthy for the individual and the communities as for the public purse” (PRIAE, 1999b: 33).

Initiatives to promote physical activity in old age must be culturally appropriate and PRIAE is in the process of developing a culturally

diverse physical activity training programme through its AIM (Ageing Actively in Minority Communities) project.

On Wednesday 7<sup>th</sup> February 2007 at Central Hall Westminster PRIAE held a South Region Conference as part of its Minority Ethnic Elders' Policy Network (ME<sup>2</sup>PN). In the workshop on Active Ageing with Mental Health, BME elders and BME age organisation managers from across London gave us the following evidence, examples and suggestions, which should inform the Mayor of London's Health Inequalities Strategy:

<p>Evidence from ME<sup>2</sup>PN South Region Conference, POLICY and PRACTICE in AGEING, Wednesday 7<sup>th</sup> February 2007, Central Hall Westminster</p> <p>Attitudes</p> <ul style="list-style-type: none"><li>• 'Many young people think that older people are mad when doing physical exercises'</li></ul> <p>Examples of good practice</p> <ul style="list-style-type: none"><li>• 'I do yoga twice a day'</li><li>• 'We have introduced Irish Dancing to older people in our community'</li><li>• 'Our centre runs cricket matches for the over 60s'</li><li>• 'We provide activities like gardening, smiling, dancing, walking, body movement for older people who visit our centre'</li></ul> <p>Suggestions</p> <ul style="list-style-type: none"><li>• 'Have special events that will bring old and young together'</li><li>• 'Use examples of activities that are recognised by BME organisations'</li><li>• 'Look at older people's past activities when introducing physical activities'</li><li>• 'Cross-cultural activities should be encouraged among older people'</li><li>• 'Community awareness on older age should be promoted'</li></ul>
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## Palliative care

In 1999 PRIAE argued for the creation of a good guide of practices which would enable BME elders to exercise their beliefs and choice on end of life issues (PRIAE, 1999b: 11).

In 2006 PRIAE made the following recommendations and observations on tackling palliative care service inequalities for minority ethnic elders:

#### Not being taken seriously

- Minority ethnic elders and carers can feel that a patient's experiences and symptoms are not taken seriously by doctors. Advocacy, intervention and support from family and friends can make a significant difference to some older people's care.

#### Language

- People who do not speak English face particular barriers in accessing and using services...For some elders who do not speak English, treatment and care can be mystifying, while also rendering them passive. The inability to communicate with minority ethnic patients can also cause dissatisfaction and stress amongst professionals...Initiatives involving multi-lingual and multi-media resources and the provision of interpreters and health advocates (bilingual interpreters trained in health advocacy and the palliative care approach) are developing within the cancer and palliative care fields....[however]...Despite growing attention to the needs of those who do not speak English, access to trained interpreters, advocates and bi-lingual professionals is highly variable across palliative care services (Gunaratnam, 2006: 19-20, PRIAE report published with NCPD).

#### Social and cultural taboos and the challenge for awareness raising

- Some cancer and palliative care services are addressing the need to work with minority ethnic voluntary and community

organisations to raise awareness of palliative care, dispel common myths and misunderstandings about illness and to promote greater access to services and support.

## Resilience

- The need for professionals to understand and build upon the sources of resilience in minority ethnic patients' and carers' lives is being recognised by researchers and palliative care professionals.

## Education and training for culturally responsive care

It has been recognised that there needs to be two-way education between specialists and generalists in order to provide better access to palliative care for those older people with non-malignant conditions. However, this recognition has not taken into account of the need for education and training to address diversity amongst older people.

In the workshop on Palliative Care at the ME<sup>2</sup>PN South Region Conference on Wednesday 7<sup>th</sup> February 2007, BME elders and BME age organisation managers from across London gave us the following evidence, examples and suggestions, which should inform the Mayor of London's Health Inequalities Strategy:

Evidence from ME<sup>2</sup>PN South Region Conference, POLICY and PRACTICE in AGEING, Wednesday 7<sup>th</sup> February 2007, Central Hall Westminster

How would you like to die?

- Die peacefully, without pain and with dignity

Are we death denying?

- People are now thinking about it in relation to finances
- Hindu religion promotes living until death
- Difficult living in a multicultural society to understand differing needs

Care homes

- Very painful to be away from social life, care homes not a good model for BME elders – 'like a fish out of water'
- Training for care home staff imperative

Where would you like to die?

- May not have choice
- Need to have discussion about choice

RECOMMENDATION: PRIAE has made a series of recommendations on

hospital care

mental health services

active ageing

palliative care

which are presented in this response. These recommendations constitute a handbook of good practice which should be utilised by the GLA in its Health Inequalities Strategy.

This response also includes messages from BME elders in London told to PRIAE at its recent Minority Ethnic Elders' Policy Network (ME<sup>2</sup>PN) conference POLICY and PRACTICE in AGEING on Wednesday 7<sup>th</sup> February 2007. These concerns from BME elders in London, and examples of good practice and recommendations, should now be utilised by the GLA in its Health Inequalities Strategy.

PRIAE would be interested to work with the GLA further to develop and implement the Mayor of London's Health Inequalities Strategy, and future work to address minority needs in old age.

ENDS/PRIAE – PRIAE response to Call for Evidence – 'Mayor of London's Health Inequalities Strategy'

This PRIAE submission was prepared by: Ian Smith, Information and Policy Manager; and with contributions from members of ME<sup>2</sup>PN through its regional conferences 2006-07.

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### Further Information about PRIAE

PRIAE is itself an international NGO set up to support grassroots minority age organisations in the civil sector, acting as an 'umbrella organisation'. The Institute therefore works with minority ethnic elders and age organisations, with clinical and non-clinical professionals and researchers, across sectors to influence, inform, develop and strengthen the knowledge base, capacity and practice in ageing and ethnicity. PRIAE welcomes the opportunity to respond the Call for Evidence – 'Mayor of London's Health Inequalities Strategy'

PRIAE is recognised as having helped to increase awareness of policymakers on the combined effects of age and ethnicity. Claude Moraes MEP states 'PRIAE is the only body I know that looks at multiple discrimination brought about by age and ethnicity'.

Stephen Hughes MEP regards PRIAE's work as a 'wake up call for policymakers' (MEC minority elderly care launch, 2004). PRIAE carried out the largest European research into health and social care of 26 ethnic groups in ten countries where 300 civil society organisations supplying age services were researched – a first of its kind research and provides European societies with important insights. The research award was given by DG Research at the EC – a first such grant to a civil society organisation in the area. The results were launched at the European Parliament ([www.priae.org](http://www.priae.org)).

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