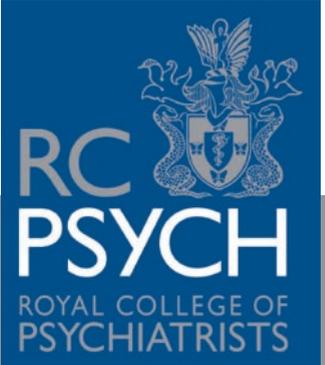


CR156



# Psychiatric services for Black and minority ethnic older people

August 2009

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College Report CR156  
August 2009

Royal College of Psychiatrists  
London

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# Executive summary and recommendations

This document looks at the mental health needs of Black and minority ethnic older people and the psychiatric services offered to this group, focusing on the main changes that have occurred since the publication of the original College report CR103 (Royal College of Psychiatrists, 2001). The main areas covered include:

- definition of Black and minority ethnic older people
- demographic changes
- review of influential publications and policy pertaining to the mental health of Black and minority ethnic groups in general and those specifically relevant to Black and minority ethnic older people
- research involving mental health issues pertaining to Black and minority ethnic older people
- current examples of good practice
- revision of recommendations as a result of this review.

## RECOMMENDATIONS

The progress of developing and improving services for Black and minority ethnic older people with mental health problems in actual practice has been slow, with only a few examples of good practice since the recommendations made in CR103 in 2001. Thus, the original recommendations of CR103 are retained:

- 1 Acute psychiatric services involving assessment and treatment should remain within mainstream psychiatric services, with ethnic awareness and sensitivity emphasised by training staff in culturally sensitive issues.
- 2 Services providing continuing care in the community should be developed specifically for the appropriate user group.
- 3 Efforts could be made to recruit a racial mix of multidisciplinary staff members reflecting the population served.
- 4 A means to share information would be to set up a website linked to the College's website.
- 5 There should be increased involvement and commitment by all interested stakeholders to involve general practitioners (GPs) and

other key players in establishing good practice for this group of service users.

The following additional recommendations are made:

- 6 There is an urgent need to identify further examples of good practice, including old age psychiatric services (OAPS) providing equitable access for Black and minority ethnic older people relative to indigenous older people. This should be possible because: all mental health service providers are now required to routinely collect data on ethnicity of service users; there are a number of studies of individual services reporting equitable access; organisations like the Policy Research Institute on Ageing and Ethnicity (PRIAE) have identified examples of good practice; and reports from the Healthcare Commission's statutory review of mental health trusts up to 2005 may also contain examples of good practice. A critical review of these data sources would allow identification of the specific components pertaining to the management, organisation and delivery of services that lead to good practice. In turn, these examples of good practice should be widely shared and promoted with all OAPS.
- 7 The College's Race Equality Action Plan also requires urgent and ongoing evaluation to establish its effectiveness in ultimately leading to better access to culturally appropriate and sensitive OAPS for Black and minority ethnic older people.
- 8 The Department of Health and other research funding bodies should give urgent consideration to funding research projects designed to evaluate the effectiveness of professional interpretation services and development of alternative methods of information sharing, including audio (cassettes and CDs), visual (videos and DVDs) and diagrammatic representations.
- 9 The Department of Health and other research funding bodies should give urgent consideration to funding research projects to develop screening and diagnostic instruments for dementia and depression in languages spoken by Black and minority ethnic older people that can be administered in English by an English-speaking clinician with the aid of a professional interpreter. Priority should also be given to projects evaluating the effectiveness of strategies promoting the use of any such instruments.
- 10 The Care Quality Commission (formerly the Healthcare Commission), along with other agencies, has so far conducted five 1-day censuses ('Count Me In') of all psychiatric in-patients in England and Wales on 31 March 2005, 2006, 2007, 2008 and 2009. Details pertaining to psychiatric in-patients aged 65 years and over by ethnicity have only been reported for the 2007 'Count Me In' survey. Such a 1-day census could be extended to include psychiatric patients in all service settings (community, out-patient clinics, day hospitals, and acute, respite and continuing care in-patient services). This would allow careful examination over time of improvement in access to all old age psychiatry settings by Black and minority ethnic older people at a national level. This collection of activity-related data should be coupled with ongoing national surveys of the experiences of a representative sample of elderly Black and minority ethnic service users pertaining to cultural sensitivity and appropriateness of OAPS. This ambitious

evaluation programme could be achieved by a collaborative effort between key organisations, including the Department of Health, the National Institute for Mental Health in England (NIMHE), the Care Quality Commission, PRIAE, the Alzheimer's Society, Age Concern and the Royal College of Psychiatrists.

The College has an important role in the pursuit of the above ambitious recommendations. This can be facilitated by the College coordinating its approach to Black and minority ethnic older people and addressing this neglected area in line with Department of Health and other central policies, new research and the Race Equality Action Plan. The Faculty of Psychiatry of Old Age could be requested to set up a working group, whose tasks would be to:

- monitor, identify and disseminate examples of good practice at a national level
- collaborate with other key organisations working with Black and minority ethnic older people
- evaluate and promote new research in this area
- regularly share this information with the College, the Faculty of the Psychiatry of Old Age and the membership in order to keep up the impetus for developing and improving services through the College's and the Faculty's network for disseminating information.

# Introduction

This document looks at the mental health needs of Black and minority ethnic older people and the psychiatric services offered to this group, focusing on the main changes that have occurred since the publication of the original College report CR103 in 2001. The main areas covered include:

- definition of Black and minority ethnic older people
- demographic changes
- review of influential publications and policy pertaining to the mental health of Black and minority ethnic groups in general and those specifically relevant to Black and minority ethnic older people
- research involving mental health issues pertaining to Black and minority ethnic older people
- current examples of good practice
- revision of recommendations as a result of this review.

# 1. Definition of Black and minority ethnic older people

The definition of 'Black and minority ethnic' older people, the term currently used for this population, requires a composite definition of old age and ethnicity. The age cut-off for old age should be the same as that used in ethnocentric old age psychiatry services, otherwise Black and minority ethnic older people are likely to receive fragmented care; this age cut-off is usually 65 years.

Race, culture and ethnicity are frequently, but erroneously, used interchangeably. Race describes the physical appearance (Bhopal, 1997); culture refers to shared features that bind individuals together into a community. The definition and identification of ethnicity is difficult (Lloyd, 1992; McKenzie & Crowcroft, 1996; Pringle & Rothera, 1996) because it includes aspects of both race and culture, as well as other characteristics such as traditions, language, religion, spirituality, upbringing, nationality and ancestral place of origin (Rait & Burns, 1997). It is also a personal expression of identity influenced by life experience and place of habitation; it is dynamic and changes over time (Senior & Bhopal, 1994). The definition of Black and minority ethnic groups used in the government document *Delivering Race Equality in Mental Health Care* (Department of Health, 2005a) was:

'all people of minority ethnic status in England. It does not only refer to skin colour but to people of all groups who may experience discrimination and disadvantage, such as those of Irish origin, those of Mediterranean origin and East European migrants.'

However, a useful working definition of ethnic minority individuals is 'those with a cultural heritage distinct from the majority population' (Manthorpe & Hettiaratchy, 1993). The latter definition was the one thought to be the best working definition in the original CR103 (Royal College of Psychiatrists, 2001).

## 2. Demographic changes

Table 1 illustrates some of the demographic characteristics of Black and minority ethnic older people ascertained from the 2001 census. In England and Wales the proportion of Black and minority ethnic older people over the age of 65 has progressively increased from 1% in the 1981 population census (Office of Population Censuses and Surveys, 1983), to 3% in the 1991 population census (Office of Population Censuses and Surveys, 1993) and 8.2% in the 2001 population census (Shah *et al*, 2005; Shah, 2007a). Moreover, 7.1% of all elderly individuals in England and Wales were from Black and minority ethnic groups in the 2001 population census, with an estimated total of 531909 (Shah, 2007a). In most Black and minority ethnic groups, the ratio of 'young-old': 'old-old' was higher than that for the

**Table 1 Demographic characteristics – summary from the 2001 population census**

<b>Ethnic group</b>	<b>Proportion of individuals aged over 65 years in ethnic group (%)</b>	<b>Young-old:old-old ratio</b>	<b>Male:female ratio</b>
Total population	15.9	0.74	0.73
White British	17.1	0.73	0.72
All Black and minority ethnic groups combined	8.2		
Irish	24.9	0.82	0.72
Other White	10.4	0.75	1.08
White and Black Caribbean	2.36	0.76	0.92
White and Black African	2.24	0.78	0.81
White and Asian	3.5	0.82	0.84
Other mixed	3.4	0.77	0.75
Indian	6.6	0.85	0.99
Pakistani	4.1	0.88	1.24
Bangladeshi	3.23	0.93	1.96
Other Asian	5.18	0.86	1.11
Black Caribbean	10.6	0.89	1.05
Black African	2.3	0.97	1.05
Other Black	3.18	0.82	0.96
Chinese	5.13	0.87	0.87
Other Black and minority ethnic groups	2.9	0.83	0.76

indigenous White British group. In most Black and minority ethnic groups the male:female gender ratio declined with increasing age, suggesting an increase in the number of women with an increase in age. This rise in the proportion and number of Black and minority ethnic older people, the higher ratio of 'young-old': 'old-old' and a different gender ratio in Black and minority ethnic groups compared with the indigenous White British group have important future implications for the current and future development and delivery of culturally appropriate and sensitive OAPS for Black and minority ethnic older people.

## 3. Review of influential publications and policies

Over the past decade, the mental health of Black and minority ethnic groups has become a national priority in the UK. When coupled with the increasing awareness regarding dementia and depression in old age, issues around the mental health of older people from Black and minority ethnic groups have become increasingly prominent. One recent study estimated the absolute number of cases of dementia in the Black and minority ethnic population to be 11 860 in the UK in 2004 (King's College London & London School of Economics, 2007). Another study estimated the absolute number of cases of dementia between 7270 and 10786 and of depression between 33559 and 52980 among Black and minority ethnic older people from all groups combined (Shah, 2008).

This research has resulted in the publication of a number of detailed governmental reports, guidelines and policies. These can broadly be divided into publications relating to Black and minority ethnic mental health in general and those relating to older people's mental health with specific mention of Black and minority ethnic groups. The most influential documents have been published directly by the Department of Health or related public bodies, including the National Institute for Mental Health in England (NIMHE), National Institute for Health and Clinical Excellence (NICE), the Care Quality Commission and the Care Services Improvement Partnership (CSIP; ceased operation on 31 March 2009).

### 3.1. NATIONAL SERVICE FRAMEWORK FOR MENTAL HEALTH

Primarily relating to 'working aged adults' (18–65 years), the *National Service Framework for Mental Health* published in 1999 was one of the first government policy documents to acknowledge disparities between Black and minority ethnic groups and the majority White population in rates of mental illness and inequalities in mental health service provision.

'Combined evidence suggests that services are not adequately meeting mental health needs, and that black and minority ethnic communities lack confidence in mental health services' (Department of Health, 1999).

The report states that mental health services should be appropriate to the needs of those who use them and non-discriminatory. Although not addressing the issues in detail, it did highlight the need for a national strategy to address the mental healthcare needs of Black and minority

ethnic groups. This contributed to the political momentum that led to the government Delivering Race Equality policy, published in 2005 (Department of Health, 2005a).

### 3.2. NATIONAL SERVICE FRAMEWORK FOR OLDER PEOPLE

The *National Service Framework for Older People* was published by the Department of Health in March 2001. Its aim was to set standards for the health and social care of older people by targeting a number of key areas. Standard seven is concerned with promoting good mental health in older people and specifically with the treatment of dementia and depression. The standards for other functional illnesses such as schizophrenia are not specifically mentioned, but are covered by the National Service Framework (NSF) for mental health (see above).

The document states that 'older people from Black and minority ethnic communities need accessible and appropriate mental health services'. It covers a number of reasons why this might not be the case, indicating that assessments may be 'culturally biased' and that assumptions are sometimes made about the willingness of families to act as primary carers for their older relatives. Also mentioned is that information about services may not be readily available in an accessible form and tends to rely on translated leaflets and posters. Although the document emphasises that mental health services should 'take account of the social and cultural factors affecting recovery and support', it makes few specific suggestions as to how cultural awareness might be improved among mental health and social care professionals.

### 3.3. FORGET ME NOT: DEVELOPING MENTAL HEALTH SERVICES FOR OLDER PEOPLE IN ENGLAND

*Forget Me Not*, the Audit Commission's analysis of mental health services for older people in England and Wales, was published in 2000 (Audit Commission, 2000) and revised in 2002 (Audit Commission, 2002). The report is consistent with the principles set out in the NSF for mental health and older people. It was largely welcomed by mental health professionals and helped to alleviate concerns that mental health in older people was being neglected by government (Benbow, 2000).

There is specific mention of the needs of Black and minority ethnic groups at several points in the document. Early on, reference is made to studies indicating that the age profile of Black and minority ethnic groups differs from the general population (mostly they are younger) and that this depends on the particular pattern of migration to Britain. The Audit Commission also states that rates of depression and dementia may be higher in some Black and minority ethnic groups and it challenges the commonly held assumption that minority ethnic and Black families 'look after their own' and have less need for services. Finally, the Commission states that when formal services are involved, 'they may be insensitive to cultural norms and may threaten carer's well-being if they do not reinforce the carer's role in an appropriate manner.'

With regard to day care, the report states that, 'Older people from minority ethnic groups need special consideration, to ensure that appropriate services are provided for them'. Although the report did not go as far as

suggesting separate services, it did recommend that this might require a change to the existing provision. Interestingly, it is quoted that Black and minority ethnic user groups do not generally request separate day centres but ask only for mainstream services to be sensitive to their needs with regard to food, language and arrangements for religious practice.

Despite the extensive recommendations in this report, there is little addressing these issues other than suggesting that information for users and carers is distributed 'in languages and formats that can be understood easily by local people'. There is virtually no mention of Black and minority ethnic groups in the 2002 revision.

### 3.4. *EVERYBODY'S BUSINESS. INTEGRATED MENTAL HEALTH SERVICES FOR OLDER ADULTS: A SERVICE DEVELOPMENT GUIDE*

Everybody's Business was launched on 14 November 2005 by the Department of Health (Department of Health, 2005b). The service development guide does not introduce any new policies, but aims to build on the service models outlined in existing documents, such as the NSF for older people and *Securing Better Mental Health for Older Adults* (Philp, 2005). It is based on the understanding that coordinating services for older people with mental health problems can be difficult as they tend to cut across the traditional social care, and mental and physical healthcare boundaries. The guide states that its aim is to 'ensure that older adults with mental health problems and their carers have their needs met, wherever they are in the system without encountering discrimination or barriers to access', and that they do not fall between gaps in services. The document provides guidance on how to develop a range of services from primary care, through to specialist mental health services, to residential and day care facilities. There is specific reference to memory assessment clinics and psychological therapies, and to the management of mental health problems in general hospitals.

Although the guide highlights the needs of a number of special groups, including those with early-onset dementia, intellectual disabilities and older prisoners, there is no specific reference to Black and minority ethnic older people other than mentioning that religious and cultural needs should be taken into account when providing service. It is worth mentioning, however, that CSIP ran a 1-year national project that aimed to promote the mental health and well-being of Black and minority ethnic older people (<http://mentalhealthequalities.org.uk/our-work/older-life/>).

### 3.5. *DELIVERING RACE EQUALITY POLICY: INSIDE OUTSIDE – IMPROVING MENTAL HEALTH SERVICES FOR BLACK AND MINORITY ETHNIC COMMUNITIES IN ENGLAND*

In 2003, NIMHE published the *Inside Outside* report (NIMHE, 2003). This document was one of the first to describe in detail the ethnic mental health inequalities both inside and outside services. Although this was previously

recognised as a problem, it had not been adequately addressed by existing mental health initiatives such as NSF for mental health or NSF for older people. *Inside Outside* again highlighted the need for a national strategy to improve the mental health within Black and minority ethnic communities and the care offered to them by mental health services. It recognised that the task would be complex and that progress and change would be:

'dependent on an inclusive process, involving politicians, policy makers, service providers from both statutory and voluntary sectors, service users and carers and most importantly, black and minority ethnic communities themselves.'

The report went on to outline the key components that should be part of the strategy to eliminate mental health inequalities:

- ensuring accountability and ownership in relation to Black and minority ethnic communities
- developing a culturally capable service
- setting national standards to improve access, care experience and outcome
- enhancing the cultural relevance of research and development.

### 3.6. *DELIVERING RACE EQUALITY IN MENTAL HEALTH CARE: AN ACTION PLAN FOR REFORM INSIDE AND OUTSIDE SERVICES*

In January 2005, the Department of Health published *Delivering Race Equality in Mental Health Care*, a 5-year action plan for achieving racial equality and tackling discrimination in mental health services in England (Department of Health, 2005a). The document was combined with the government's response to the recommendations made by the independent inquiry into the death of David Bennett, a 38-year-old African-Caribbean patient who died in a psychiatric unit having been restrained by staff.

The Delivering Race Equality policy applies to all those with Black and minority ethnic status including those of Irish, Mediterranean and East European origin, and covers all age ranges from childhood to old age. It is based on three building blocks:

- 1 more appropriate and responsive services: specifically mentioning the improvement of clinical services for groups including older people, asylum seekers and children
- 2 community engagement: aiming to engage communities in planning services with the recruitment of new community development workers
- 3 better information: improved monitoring of ethnicity, better dissemination of information and good practice and a new regular census of mental health patients (see Count Me In census in section 3.7 below).

The document acknowledges that older people from Black and minority ethnic communities face the double jeopardy of old age and ethnic

minority status – they can be marginalised in society and have specific needs. Potential difficulties around communication, particularly written materials, are highlighted, as is the need for services to provide adequate interpretation facilities. The Department of Health mentions that the National Health Service (NHS) primary care trusts need to acquire 'Black and minority ethnic age-specific expertise' in order to develop culturally appropriate and responsive services (Department of Health, 2005a). This is to be facilitated by NIMHE in collaboration with the voluntary sector, including Age Concern, the Alzheimer's Society and PRIAE.

### 3.7. 'COUNT ME IN' CENSUS

As stipulated in the *Delivering Race Equality in Mental Health* action plan, March 2005 saw the first national mental health Count Me In census (Healthcare Commission, 2005). The census is a count of all patients in mental health and intellectual disability beds in England and Wales on one day and is scheduled annually until 2010. It is a joint initiative between the Care Quality Commission and NIMHE. The purpose of the census is to obtain reliable data on all mental health in-patients with regard to their admission and demographic characteristics, including ethnicity, language and religion. This information is designed to assist healthcare providers in achieving the government's Delivering Race Equality objectives.

Data published from the first three censuses showed similar findings. In the 2007 census, 22% of in-patients were from Black and minority ethnic groups, although in the general population this is less than 10%. Admission rates were particularly high in people from African or African-Caribbean descent (9%) and they were more likely than average to have been referred through the criminal justice system and detained under the Mental Health Act 1983.

One criticism of the 2006 survey was that although one-third of the 32000 patients were over 65 years of age, no separate analysis was conducted for this age group (Shah & McKenzie, 2007a). This was rectified for the 2007 census. The 2007 Count Me In survey of all psychiatric in-patients on 31 March 2007 in England and Wales estimated that the standardised admission ratio (with the rate for England and Wales being the standard) for those aged 65 years and over were: higher in the White Irish, other White, other Asian, Black Caribbean, Black African and other Black groups; lower in the White British and Chinese groups; and not significantly different in the Indian, Pakistani and Bangladeshi groups (Commission for Healthcare Audit and Inspection, 2007). Similar findings were observed in the 2008 census. Findings of the 2009 census are awaited.

### 3.8. NICE GUIDELINES ON DEMENTIA

The National Institute for Health and Clinical Excellence published its clinical guideline on dementia in 2008 (National Collaborating Centre for Mental Health, 2008). It makes specific recommendations on Alzheimer's disease, dementia with Lewy bodies, frontotemporal dementia, vascular dementia and mixed dementias, as well as general recommendations that apply to all types of dementia. The guideline incorporates recommendations from NICE's

technology appraisal of donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease (see section 3.9).

One of the key principles of care outlined in this document relates to diversity (gender, ethnicity, age or religion), with a strong emphasis on 'person-centered care'. Although there is no mention of specific Black and minority ethnic groups, the guideline advocates that the needs and preferences of individuals with dementia relating to diversity must be identified and, where possible, accommodated. Language is also mentioned as a possible barrier to care, with recommendations that interpreters should be readily available and that written information should be provided in the preferred language and/or an accessible format.

### 3.9. NICE GUIDANCE ON CHOLINESTERASE INHIBITORS

The first NICE technological appraisal for the use of donepezil, galantamine and rivastigmine for the treatment of mild-to-moderate Alzheimer's disease was published in 2001. A draft review in 2005 recommended that these drugs were not cost-effective and that they should not be prescribed on the NHS. This met huge opposition and an amended version of the appraisal taking account of subgroup analysis was issued in May 2006, restricting the use of cholinesterase inhibitors to the moderate stages of dementia. Five appeals were lodged by an alliance of professional and voluntary bodies, but the appraisal was upheld following a judicial hearing in July 2006.

Interestingly, the guidelines were amended after the judicial review in August 2007 and reissued in November of the same year (NICE, 2007). The guidance was found to be unlawful because it breached the Race Discrimination Act and the Disability Discrimination Act as it discriminated against people from different ethnic backgrounds, particularly those whose first language is not English, and people with disabilities, based on its reliance on the Mini-Mental State Examination (MMSE) as an assessment tool. Essentially a screening tool, the MMSE is not always valid in people from different cultural backgrounds, particularly non-English speakers, and can lead to an overdiagnosis of dementia. The amended appraisal recognises this, allowing for greater flexibility and advocating the use of more appropriate methods of assessment. The guidelines state that:

'In determining whether a patient has Alzheimer's disease of moderate severity, healthcare professionals should not rely solely upon the patient's MMSE score in circumstances where it would be inappropriate to do so.'

The guideline also stresses the need to 'secure equality of access to treatment for patients from different ethnic groups (in particular those from different cultural backgrounds) and people with disabilities'.

This recognition of the specific needs of Black and minority ethnic older people by government and its incorporation into guidelines and policy represents a significant step forwards.

### 3.10. NATIONAL DEMENTIA STRATEGY FOR ENGLAND

The national dementia strategy was published early this year (Department of Health, 2009). The strategy has three main objectives:

- 1 to improve awareness of dementia, among both the public and professionals
- 2 to promote early and accurate diagnosis and intervention.
- 3 to deliver high-quality care and support for dementia sufferers and their carers.

This national strategy recognises the importance of ethnicity, culture, religion and language in the systematic development of dementia services, and advocates that services are developed for such diverse groups.

### 3.11. DEMENTIA UK REPORT

This recent, influential report, detailing the prevalence and cost of dementia, was commissioned by the Alzheimer's Society and produced jointly by the London School of Economics and the Institute of Psychiatry, King's College London (King's College London & London School of Economics, 2007). Although not a governmental report, it provides the most comprehensive, up-to-date summary of dementia in the UK and gives projections for the future. The document concludes with seven key recommendations:

- 1 make dementia a national priority
- 2 increase funding for dementia research
- 3 improve dementia care skills
- 4 develop community support
- 5 guarantee carer support packages
- 6 hold a national debate on who pays for care
- 7 develop comprehensive dementia care models.

Although detailed in many areas, this report only briefly describes dementia in relation to Black and minority ethnic groups and does not mention it at all in the recommendations. It estimates that in total there are nearly 11860 individuals with dementia in the UK from Black and minority ethnic communities. This, however, is based on the assumption that the prevalence in these groups is the same as for the general population and it may be an underestimate. Although the research group was unable to calculate the projected increases in absolute numbers, they were able to predict with confidence a significant increase in the proportion of Black and minority ethnic older people with dementia as compared with the general population. This is because the large numbers of people who migrated to the UK from the Caribbean, the Indian subcontinent and China in the 1950s, 60s and 70s are now entering old age and are therefore at increased risk of developing dementia.

### 3.12. *IMPROVING SERVICES AND SUPPORT FOR PEOPLE WITH DEMENTIA* – NATIONAL AUDIT OFFICE

Another dementia report highlighting the need for a national strategy was published in July 2007 by the National Audit Office. The investigation

examines 'what health and social care services are available for people with dementia and their unpaid carers and whether they are providing effective and good quality support; and the scope for better use of resources against a background of rising demand' (National Audit Office, 2007).

The report was compiled from data provided by the Alzheimer's Society UK Dementia report (see section 3.11), and from focus groups, internet web forums and surveys of individuals with dementia, professionals and carers.

The report concludes that, overall, services are not delivering value for money to taxpayers or people with dementia and their families:

- health and social care services are spending significantly on dementia
- spending is late – too few people are being diagnosed or diagnosed early enough. Early interventions that are known to be cost-effective, and which would improve quality of life, are not being made widely available; this results in spending at a later stage on necessarily more expensive services
- services in the community, care homes and at the end of life are not delivering consistently or cost-effectively against the objective of supporting people to live independently as long as possible in the place of their choosing.

A number of recommendations are made, but with no reference to Black and minority ethnic groups.

### 3.13. KING'S FUND REPORT: *PAYING THE PRICE*

A recent King's Fund Report, *Paying the Price: The Cost of Mental Health Care in England to 2026*, provided detailed information on the current and the projected need for mental health services, and the associated costs (McCrone *et al*, 2008). This report covered all age ranges and included data for dementia and depression, the two most prevalent mental disorders in old age. A particularly strong emphasis was given to dementia and it was pointed out that dementia is the most costly of all mental disorders, with a projected cost of £34.8 billion by 2026. Although this report provided data on the projected population over the age of 60 years for several amalgamated Black and minority ethnic groups, there was no specific reference to Black and minority ethnic groups in the report's recommendations.

## 4. Research relevant to mental health needs of Black and minority ethnic older people

Research pertaining to Black and minority ethnic older people and mental illness has been conducted in several areas:

- population-based epidemiological studies of prevalence
- prevalence studies of convenience samples
- studies of risk and protective factors
- non-cognitive symptoms of dementia
- service evaluation
- knowledge and uptake of services
- awareness of depression and dementia
- genetics
- inflammatory markers
- normative data for instruments measuring cognitive impairment
- development of screening instruments for dementia and depression
- suicides.

### 4.1. POPULATION-BASED EPIDEMIOLOGICAL STUDIES OF PREVALENCE

Dementia and depression are the most prevalent mental disorders in the elderly. The prevalence of dementia and depression among older people from different Black and minority ethnic groups in the UK, from population-based epidemiological studies, is generally similar to or higher than that among indigenous older people (Bhatnagar & Frank, 1997; Lindesay *et al*, 1997a; McCracken *et al*, 1997; Richards *et al*, 2000; Livingston *et al*, 2001); unpublished work from one of the author's (S.A.) research group suggests that the prevalence of dementia is higher in older African-Caribbean people. The prevalence of dementia was higher in Black and minority ethnic older

people who were unable to speak English (McCracken *et al*, 1997). The Leicester study of elderly Gujaratis (Lindesay *et al*, 1997a) had additional evidence of validity of the diagnosis of dementia, whereby the diagnosis of dementia was confirmed at 27-month follow-up in all but one of the cases (Shah *et al*, 1998). The Leicester study of Gujarati older people (Lindesay *et al*, 1997a) and the Bradford study of older people of Indian subcontinent origin (Bhatnagar & Frank, 1997) also reported prevalence of other psychiatric disorders, including anxiety disorders, agoraphobia, simple phobia and panic attack.

## 4.2. PREVALENCE STUDIES OF CONVENIENCE SAMPLES

The prevalence of depression in convenience samples of elderly Bengalis and Somalis in east London was higher than in the indigenous White British group (Silveira & Ebrahim, 1995, 1998a,b), but lower in a convenience sample of elderly Gujaratis in north London (Ebrahim *et al*, 1991; Silveira & Ebrahim, 1998a,b). Although there are no population-based studies of late-onset schizophrenia, one study reported an increased rate of new contacts with services among African-Caribbean older people compared with the indigenous older people (Reeves *et al*, 2001).

## 4.3. RISK AND PROTECTIVE FACTORS

Depression among Black and minority ethnic older people from several different groups has been shown to be associated with chronic health problems, stroke, subjective ill health, functional disability, increasing age, poor housing, low family support, reported need for community services, poor socioeconomic status, female gender and poor fluency in English (Silveira & Ebrahim, 1995, 1998b; McCracken *et al*, 1997; Livingston *et al*, 2001; Stewart *et al*, 2001a).

Dementia among Black and minority ethnic older people from several different groups has been shown to be associated with increasing age, lower levels of education, poor fluency in English and being in a residential or a nursing home (McCracken *et al*, 1997; Livingston *et al*, 2001).

Among African-Caribbean older people with low levels of education, cognitive impairment (as opposed to a diagnosis of dementia) was associated with hypertension, diabetes and raised triglyceride levels; among African-Caribbean older people with normal or higher levels of education, cognitive impairment was associated with high cholesterol levels and manual occupation (Stewart *et al*, 2001b). Physical exercise offered protection against cognitive impairment (Stewart *et al*, 2001b).

Cognitive decline, over a 3-year period, in African-Caribbean older people was associated with ageing; this decline was significantly stronger in those with diabetes mellitus, but lower in those reporting vigorous physical exercise at baseline (Stewart *et al*, 2003). Shorter leg length, independent of age, gender and education, was associated with cognitive impairment but not cognitive decline in African-Caribbean older people (Mak *et al*, 2006).

Elderly Hindu grandmothers in London were better psychologically adjusted if they lived in extended households and had grand-daughters with exclusively 'Indian' or 'Hindu' ethnic identity (Guglani *et al*, 2000).

## 4.4. BEHAVIOURAL AND PSYCHOLOGICAL SIGNS AND SYMPTOMS OF DEMENTIA

Only one study has examined the prevalence and correlates of behavioural and psychological signs and symptoms of dementia – in a convenience sample of day-hospital patients of Indian subcontinent origin with dementia (Haider & Shah, 2004).

## 4.5. SERVICE EVALUATION

There have been a small number of studies evaluating the equity of access to OAPS and other specific service provisions. Two separate studies of older people of Indian subcontinent origin, in two separate services in west London, demonstrated equity of access to the local OAPS and to the specific components of the service (Redelinguys & Shah, 1997; Odutoye & Shah, 1999). The same was observed in older people of Polish origin in west London (Bhatkal & Shah, 2004). Utility of community services by community-dwelling Black and minority ethnic older people in London from several groups (Livingston *et al*, 2002) and African-Caribbean older people (Richards *et al*, 1998), compared with indigenous older people, were similar.

## 4.6. KNOWLEDGE AND UPTAKE OF SERVICES

Black and minority ethnic older people are often unaware of available services and of the procedures to apply for these services, are more likely to be turned down for services and, if accepted, are more likely to be dissatisfied (Lindesay *et al*, 1997b; Bowes & Wilkinson, 2003). However, there is evidence that this may be changing (Redelinguys & Shah, 1997; Richards *et al*, 1998; Odutoye & Shah, 1999; Livingston *et al*, 2002; Bhatkal & Shah, 2004).

## 4.7. AWARENESS OF DEPRESSION AND DEMENTIA

African-Caribbean older people compared with White British older people in Islington were more likely not to view depression as an illness, choose not to consult their GP or psychiatric services, perceive depression as stigmatising, and feel that spiritual help may be more appropriate (Marwaha & Livingston, 2002).

White British, south Asian and African-Caribbean older people viewed depression as an illness arising from adverse personal and social circumstances related to old age, and those receiving antidepressants were more likely to acknowledge psychological symptoms of depression (Lawrence *et al*, 2006a). White British and African-Caribbean older people defined depression in terms of low mood and hopelessness. African-Caribbean and south Asian older people defined depression in terms of worry. African-Caribbean, south Asian and White British older people with treated and untreated depression expressed a willingness and desire to talk about psychological problems, but felt there was insufficient time to do

this with their GP (Lawrence *et al*, 2006b). African–Caribbean older people reported that conversing with God through prayer was an effective means of overcoming depression, but south Asians identified family as an important source of help; only 10% thought that seeing a psychiatrist was helpful.

Although both Indian and White British older people in Manchester had poor knowledge of dementia, it was worse among Indian older people (Purandare *et al*, 2007). South Asians with dementia in Scotland had negative experience of dementia, poor quality of life, desperate need for support, little knowledge of dementia, and experienced isolation from the community and family life (Bowes & Wilkinson, 2003). A study of south Asian and African–Caribbean carers of individuals with dementia observed that awareness of dementia and the understanding of the causes of dementia was poor (Adamson, 2001).

An elegant study using the principles of community engagement developed by the University of Central Lancashire reported that over 80% of elderly Chinese in Manchester were aware of dementia (Wai Yin Chinese Women Society, 2007). They were also aware that dementia is associated with memory loss, problems with speech and mobility, ageing and brain disease. However, they were unlikely to seek help from their GP because of difficulty in communication due to language barriers and fear of stigma attached to mental illness.

## 4.8. GENETICS

Genetic studies have been conducted only in the African–Caribbean elderly group in the UK. Cognitive impairment was negatively associated with *APOE E2* allele and positively, but more weakly, with the *APOE E4* allele (Stewart *et al*, 2001c). The effect of both alleles was greater after the age of 70, and greater in those with hypertension, diabetes mellitus and lower levels of educational attainment. Subjective memory impairment in African–Caribbean older people was associated with depression, self-reported physical impairment and *APOE E4* allele (Stewart *et al*, 2001d); the effect of *APOE E4* allele was stronger in those with depression and lower cognitive scores on the MMSE. There was no direct association between Angiotensin I converting enzyme genotype and cognitive decline, although the *ACE DD* genotype strengthens the association between cognitive decline and age (Stewart *et al*, 2004).

## 4.9. INFLAMMATORY MARKERS

Raised levels of one inflammatory marker (IL-6) were associated with cognitive decline among African–Caribbean older people (Jordanova *et al*, 2007).

## 4.10. NORMATIVE DATA

Normative data on some cognitive batteries, including the MMSE, the Consortium to Establish a Registry for Alzheimer’s Disease (CERAD) battery and clock drawing, are available for African–Caribbean older people (Stewart *et al*, 2001e, 2002).

## 4.11. DIAGNOSTIC AND SCREENING INSTRUMENTS

Screening instruments developed for use in older people from Black and minority ethnic groups in the UK are discussed in this section. The MMSE has been developed in Hindi, Punjabi, Urdu, Bengali and Gujarati (Lindesay *et al*, 1997a; Rait *et al*, 2000a), and in English for use in the African-Caribbean group (Rait *et al*, 2000a). The abbreviated Mental Test Score (Quereshi & Hodkinson, 1974) has been developed in several Asian languages and in English for use among African-Caribbeans in the UK (Rait *et al*, 1997, 2000a,b).

Three depression screening instruments: the 15-item Geriatric Depression Scale (Sheikh & Yesavage, 1986), Brief Assessment Schedule Cards (Adshead *et al*, 1992) and Caribbean Culture-Specific Screen (Abas *et al*, 1998) for UK African-Caribbean elders were successfully evaluated against a 'gold standard' diagnosis of depression on the Geriatric Mental State (Rait *et al*, 1999). All three instruments showed satisfactory sensitivity and specificity in detecting depression in older Jamaicans, with little difference between the three scales. The Caribbean Culture-Specific Screen was developed *a priori* by ascertaining terminology used to describe emotional distress using various techniques described earlier (Abas *et al*, 1996). In general, lower cut-off scores have been suggested on some scales, like the Geriatric Depression Scale (Sheikh & Yesavage, 1986) for African-Caribbean older people in the UK (Abas *et al*, 1998).

The difficulty with all the screening instruments for depression and dementia is that they can only be used by bilingual clinicians because the questions are in the patient's language. There are no instruments that can be administered by English-speaking clinicians in English, with an interpreter translating the question to the patient and the answer to the clinician, and with the clinician scoring. Furthermore, there are no diagnostic instruments for use in Black and minority ethnic elderly groups.

## 4.12. SUICIDES

Only three studies have examined suicides in Black and minority ethnic elderly groups (Raleigh *et al*, 1990; Neeleman *et al*, 1997; Shah *et al*, 2009b): two of those were part of larger studies of suicide across all age groups (Raleigh *et al*, 1990; Neeleman *et al*, 1997), and the third study was confined to older migrants and compared suicide rates in older migrants with those in older people in England and Wales and in the country of their origin (Shah *et al*, 2009b).

## 4.13. RESEARCH WORK FROM POLICY RESEARCH INSTITUTE ON AGEING AND ETHNICITY

The Policy Research Institute on Ageing and Ethnicity (PRIAE) conducted a large cross-national study involving several European countries, the Care Needs of Ethnic Older People Suffering from Alzheimer's (CNEOPSA) project ([www.priae.org/publications.htm](http://www.priae.org/publications.htm)). The main findings were:

- individuals with dementia and their carers who do not speak English faced problems at every stage when trying to get care
- Black and minority ethnic families had difficulty in communicating with professionals and acquiring information about available services
- Black and minority ethnic individuals faced huge difficulties in accessing services because of a complex system involving several agencies
- many cultural groups failed to recognise dementia as an illness and attributed dementia to growing old, and consequently carers looked after the person with dementia without seeking help
- there was inadequate funding for day centres and voluntary organisations who could provide culturally sensitive services for Black and minority ethnic person with dementia
- the need for training, training materials, policy development and further research was identified.

Other work from PRIAE has demonstrated that the importance of stigma and all the above issues were leading to late presentation and late diagnosis of dementia (Patel *et al*, 1998).

#### 4.14. CARER ISSUES

Caregiving for dementia among Asian groups has been shown to be determined by gender stereotypes and filial responsibility (Townsend & Godfrey, 2001), and Black and minority ethnic carers tend to care unaided and in isolation (Seabrooke & Milne, 2004). However, the experiences of Black and minority ethnic carers have been shown to be similar to White British carers (Adamson, 1999). Nevertheless, there is a paucity of studies examining issues relevant to caregivers of Black and minority ethnic older people (Milne & Chryssanthopoulou, 2005).

#### 4.15. MISCELLANEOUS

Diagnostic difficulties in assessing Gujarati older people experienced by a Gujarati-speaking psychiatrist have been described (Shah, 1992, 1999).

Idioms used to express emotional distress by African–Caribbean older people have been described (Abas, 1996; Abas *et al*, 1996, 1998).

## 5. Current examples of good practice

Despite the number of guidelines and policies reviewed above and extensive research in several areas involving psychiatric aspects of Black and minority ethnic older people, examples of good practice are relatively few. There are, however, a series of editorials, commentaries, literature reviews and guidance based on the literature and anecdotal experience pertaining to the assessment, service provision and carer issues for Black and minority ethnic older people with mental illness (Shah, 1992, 1997, 1998, 2001, 2007*b*; Rait *et al*, 1996; Rait & Burns, 1997, 1998; Ghosh, 1998; Lindesay, 1998; Patel & Mirza, 2001; Livingston & Sembhi, 2003; Milne & Chryssanthopoulou, 2005; Shah *et al*, 2005, 2006, 2008, 2009*a*; Shah & Mackenzie, 2007*b*). One such guidance is for elderly refugees and asylum seekers (Shah *et al*, 2009*a*). PRIAE have commissioned a guide for the assessment of dementia in Black and minority ethnic individuals that will be published in late 2009.

The examples of good practice observed in OAPS with equity of access include:

- employment of bilingual healthcare workers
- employment of bilingual community psychiatric nurses
- ready availability of professional interpreters
- staffing composition reflecting local demography
- close collaboration with the local voluntary sector catering for Black and minority ethnic older people and their carers (Redelinghuys & Shah, 1997; Hoxey *et al*, 1999; Odutoye & Shah, 1999; Bhatkal & Shah, 2004).

Some OAPS and voluntary sector organisations catering for Black and minority ethnic older people have translated leaflets in several Black and minority ethnic languages, but these are not always helpful as a significant number of Black and minority ethnic older people are unable to read their mother tongue. We are unaware of any services where audio (cassette or CD) format of translated leaflets are made available to Black and minority ethnic older people or their carers.

Innovative multidisciplinary staff in OAPS and residential and nursing homes have developed a way of improving communication on day-to-day matters by asking either relatives or visiting interpreters to write down commonly used phrases and questions in the patient's mother tongue with paraphrases in English for staff to read out if the patient cannot read his or her mother tongue.

There are very helpful directional signs in two common Black and minority ethnic languages (Gujarati and Punjabi) throughout the Sidney Brandon Mental Health Unit in Leicester.

PRIAE developed an excellent video *Dementia Matters, Ethnic Concerns*, which was aimed at Black and minority ethnic older people, professionals and policy makers to raise awareness and set the context for key issues to address in Black and minority ethnic dementia care. Alzheimer's Concern Ealing (tel: 020 8568 4448) have developed an excellent educational video in Punjabi for carers and individuals with dementia. The Alzheimer's Society have produced a film called *Remember Me* for African-Caribbean individuals with dementia and their carers (available from their Dementia Knowledge Centre, tel: 0845 130 2545; email: [knowledgecentre@alzheimers.org.uk](mailto:knowledgecentre@alzheimers.org.uk)). The Alzheimer's Society have also recently developed a DVD entitled *Kal Ki Baat* for carers and people with dementia, based on a fictional story with commentary from professionals in several south Asian languages including Hindi, Urdu and Gujarati (tel: 01904 633 804).

Age Concern in Camden (tel: 020 7837 3777) is developing a Black and minority ethnic 'talking therapies' service, available in several languages.

PRIAE is currently developing a training programme with a range of partner organisations and Black and minority ethnic older people, with three sequential stages:

- 1 providing training to Black and minority ethnic voluntary sector organisations in local referral pathways for dementia and depression
- 2 cultural competency training
- 3 training Black and minority ethnic older people on care pathways, available resources and local information points for depression and dementia.

It is hoped that Black and minority ethnic older people will become informal advocates for their peers, friends and colleagues in their social networks.

The Care Services Improvement Partnership's Older People's Mental Health Programme (CSIP has now ceased to exist, but the details of the programme are available on the following website: <http://www.mentalhealthequalities.org.uk/our-work/older-life/>) ran a 1-year national project to promote the mental health and well-being of Black and minority ethnic older people and to improve their access to mental health services. This included national mapping of resources and projects for Black and minority ethnic older people, details of which are available on the above website. This includes an educational film on depression for the Bangladeshi group, a DVD raising awareness of depression and promoting actions to achieve a 'healthy mind and healthy body' for the Chinese group, and resource packs and leaflets for depression for other Black and minority ethnic groups, including those for Irish Traveller and Romany Gypsy groups.

## 6. Revision of recommendations

The recommendations made in CR103 in 2001 were that:

- 1 Acute psychiatric services involving assessment and treatment should remain within mainstream psychiatric services, with ethnic awareness and sensitivity emphasised by training staff in culturally sensitive issues.
- 2 Services providing continuing care in the community should be developed specifically for the appropriate user group.
- 3 Efforts could be made to recruit a racial mix of multidisciplinary staff members reflecting the population served.
- 4 A means to share information would be to set up a website linked to the College's site.
- 5 There should be increased involvement and commitment by all interested stakeholders to involve general practitioners and other key players in establishing good practice for this group.

This review provides a chance to revise these recommendations in view of the large body of new information (detailed above) that is now available. However, it is disappointing to acknowledge that the progress of developing and improving services for Black and minority ethnic older people with mental health problems in actual practice has been slow, with only a few examples of good practice. All five recommendations from 2001 should therefore be retained as recommendations in this review.

The following additional recommendations are made:

- 6 There is an urgent need to identify further examples of good practice, including old age psychiatric services (OAPS) providing equitable access for Black and minority ethnic older people relative to indigenous older people. This should be possible because: all mental health service providers are now required to routinely collect data on ethnicity of service users; there are a number of studies of individual services reporting equitable access; organisations like the Policy Research Institute on Ageing and Ethnicity (PRIAE) have identified examples of good practice; and reports from the Healthcare Commission's statutory review of mental health trusts up to 2005 may also contain examples of good practice. A critical review of these data sources would allow identification of the specific components pertaining to the management, organisation and delivery of services that lead to good practice. In turn, these examples of good practice should be widely shared and promoted with all OAPS.

- 7 The College's Race Equality Action Plan also requires urgent and ongoing evaluation to establish its effectiveness in ultimately leading to better access to culturally appropriate and sensitive OAPS for Black and minority ethnic older people.
- 8 The Department of Health and other research funding bodies should give urgent consideration to funding research projects designed to evaluate the effectiveness of professional interpretation services and development of alternative methods of information sharing, including audio (cassettes and CDs), visual (videos and DVDs) and diagrammatic representations.
- 9 The Department of Health and other research funding bodies should give urgent consideration to funding research projects to develop screening and diagnostic instruments for dementia and depression in languages spoken by Black and minority ethnic older people that can be administered in English by an English-speaking clinician with the aid of a professional interpreter. Priority should also be given to projects evaluating the effectiveness of strategies promoting the use of any such instruments.
- 10 The Care Quality Commission (formerly the Healthcare Commission), along with other agencies, has so far conducted five 1-day censuses ('Count Me In') of all psychiatric in-patients in England and Wales on 31 March 2005, 2006, 2007, 2008 and 2009. Details pertaining to psychiatric in-patients aged 65 years and over by ethnicity have only been reported for the 2007 'Count Me In' survey. Such a 1-day census could be extended to include psychiatric patients in all service settings (community, out-patient clinics, day hospitals, and acute, respite and continuing care in-patient services). This would allow careful examination over time of improvement in access to all old age psychiatry settings by Black and minority ethnic older people at a national level. This collection of activity-related data should be coupled with ongoing national surveys of the experiences of a representative sample of elderly Black and minority ethnic service users pertaining to cultural sensitivity and appropriateness of OAPS. This ambitious evaluation programme could be achieved by a collaborative effort between key organisations, including the Department of Health, the National Institute for Mental Health in England (NIMHE), the Care Quality Commission, PRIAE, the Alzheimer's Society, Age Concern and the Royal College of Psychiatrists.

The College has an important role in the pursuit of the above ambitious recommendations. This can be facilitated by the College coordinating its approach to Black and minority ethnic older people and addressing this neglected area in line with Department of Health and other central policies, new research and the Race Equality Action Plan. The Faculty of Psychiatry of Old Age could be requested to set up a working group, whose tasks would be to:

- monitor, identify and disseminate examples of good practice at a national level
- collaborate with other key organisations working with Black and minority ethnic older people
- evaluate and promote new research in this area

- regularly share this information with the College, the Faculty of the Psychiatry of Old Age and the membership in order to keep up the impetus for developing and improving services through the College's and the Faculty's network for disseminating information.

There is a high risk that unless a working group is set up, by the time of the next review we will once again be faced with very limited progress in service development and good practice.

# Summary

This review sets out a very comprehensive account of all demographical changes, influential publications and policy, research and current examples of good practice concerning Black and minority ethnic older people and their mental health needs. We support retaining the original recommendations of the College Report CR103 and make new ambitious recommendations that require strong input from the College and other organisations working with Black and minority ethnic older people in order to make progress in this field. This is a challenge that should be taken up – there is a need for more service and research development for mental health needs of Black and minority ethnic older people as, regrettably, this is still a neglected area. This review should be widely disseminated by the College as it will also serve as a reference document for all mental health practitioners working with Black and minority ethnic older people.

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