Section 3 - Ethnicity and Dementia

Bradford and Airedale contains a rich mix of Black, Minority and Ethnic (BME) groups and cultures and it is important that Health Needs Assessments consider the potential impact of this on epidemiology and services. This section summarises the ethnic composition of the district and current services for ethnic minority groups, explains the key issues relating to ethnicity and dementia, highlights the relevant key findings in the Health Needs Assessment, explores some of the (sadly limited) published evidence on effectiveness of interventions, and makes recommendations as to possible next steps.

The Ethnic Composition of Bradford and Airedale

The key statistics are as follows:

• Approximately 75% of the district’s population is estimated to be white.
• The second largest ethnic group is people with an Asian heritage (20%).
• Only a small proportion of the district’s population are from mixed, black and other ethnic groups, 1.9%, 1.7% and 1.2 % respectively.
• The ethnic minority population sub groups tend to be younger than the average for the district, with only 8% of the existing retirement age population having an Asian background. This compares to 30% of all 0 to 15 year olds.
• Of the Bangladeshi population, 37% are under 16 years of age. The corresponding figure for the Pakistani population is 34%, compared to 19% for the White population in the district.

As the population of the district increases in future years, Bradford’s ethnic composition is also expected to change significantly. Leeds University’s School of Geography, using Office for National Statistics (ONS) population projections based on 2006 estimates and their ethnic group projection model, predict that between 2006 and 2031, the White population levels will remain fairly constant. However, as the size of other ethnic groups increase, the proportion of the population classified as White will fall to 56%. It is anticipated that the Asian sub group will experience a significant increase, partly due to the number of individuals that moved to the UK between the 1950s and 1970s (1). It is expected that it will increase by approximately 132,000 between 2006 and 2031, an increase of 130%, so that by 2031 the Asian population will constitute 35% of the district population. It is also expected that the remaining ethnic groups will also experience an increase, although at a much lower rate.
Key Issues Relating to Ethnicity and Dementia

1. Although no specific comparative epidemiological data are currently available on the incidence and prevalence of dementia across different ethnic groups, it is likely that dementia will be more common among Asian and Black Caribbean elders. This is because high blood pressure, diabetes, stroke and heart disease, which are associated with vascular dementia, are more common in these communities \(^{(2, 3, 4)}\).

2. People from Black and Minority Ethnic Communities are more likely to develop Early Onset Dementia, although the numbers of this type of dementia across the District are small (see Section 16 – Early Onset Dementia). They also tend to access dementia services later, which can have a negative impact on families as they may have struggled for longer without support \(^{(5)}\).

3. Most studies have found that education is protective against both the development and the progression of dementia \(^{(6, 7, 8, 9)}\). Migrant groups with relative socio-economic deprivation, often associated with less education, might therefore be expected to be more vulnerable to dementia. The relative youth of the ageing immigrant population compared with the ageing indigenous population would then decrease the overall prevalence.

4. A key limiting factor in understanding the relationship between ethnicity and dementia is the relatively poor quality of recording and coding of ethnicity status \(^{(10)}\) (this is not something particular to Bradford and Airedale).

5. The proportion of older people from ethnic minority groups in the UK is small, but increasing steadily as this section of the population ages. It is therefore predicted that the number of people with dementia from BME groups will rise quickly \(^{(11)}\).

6. NICE Guidance on Dementia clearly emphasises that health and social care staff should identify the specific needs of people with dementia and their carers arising from ethnicity, and that care plans should record and address these needs \(^{(12)}\).

7. It is noteworthy that 6.1% of all people with dementia among BME groups are early onset, (see Section 16 – Early Onset Dementia) compared with only 2.2% for the UK population as a whole, reflecting the younger age profile of BME communities \(^{(13)}\).

8. It is broadly acknowledged that ethnic minority group status can negatively impact upon the uptake of services for both people from ethnic minority groups and younger people with dementia \(^{(14)}\). However, a recent English study of the impact of ethnicity on health seeking behaviours found that ealth seeking behaviour did not vary by ethnic density \(^{(15)}\).
9. The use of standard screening instruments that rely on language recognition and familiarity with test situations may be inappropriate or misleading for people with cognitive impairment. Culturally appropriate norms are also important in the evaluation of dementia. Immigrants may be literate in a different language or functionally illiterate. Recent immigrants from rural areas may have had little need for the concept of complex maps and exact dates. As a result, interpreting cognitive testing without a knowledge of education and background is likely to lead to errors in diagnosis. It may be important, therefore, to develop, validate and modify screening tools.

10. Studies have found that levels of stigma may be higher among Asian, Irish, Black Caribbean and Eastern European older people and carers. Religious beliefs may account for some stigma among Asian people. Research with Black Caribbean and Irish people suggests they are more inclined to see dementia as a ‘mental illness’, rather than the result of physiological changes in the brain. Among Eastern Europeans, stigma may relate to experiences of persecution and the need to ‘keep face’.

11. The published evidence does provide some examples of ways in which services or researchers have been successful in publicising information about dementia and improving awareness among BME communities, particularly where attempts have been made to do this in conjunction with local communities. Examples include:
   - Using neutral language in leaflets, such as ‘memory problems’ for dementia. This avoids making assumptions that people understand what is meant by these terms
   - Developing a multi-purpose leaflet instead of individual leaflets from each separate service. Such a leaflet would include information about memory problems and about what sort of help is available
   - Holding ‘roadshows’ at religious establishments and community centres
   - Providing DVDs or videos about dementia. This approach is particularly useful where members of a community are neither literate in English nor their mother tongue
   - Publicising information on local radio stations
   - Creating links with local communities – for instance, at places of worship
   - Appointing outreach workers

12. A detailed (though not peer reviewed) study of dementia in the Asian community in Kent found a striking lack of knowledge and understanding of dementia in the Asian community. They did not conceptualise the illness as an organic disease or treatable illness, and Asian languages did not seem to have an equivalent word for dementia. There was an almost universal negative perception of dementia, and this negative
perception, coupled with a lack of knowledge about treatment and services, acted as a powerful barrier to both users and carers seeking support. Cultural beliefs and issues around confidentiality also played a role, and considerable stigma was associated with acknowledging dementia.

Many Asians came to the attention of services at an advanced stage of dementia, severely limiting opportunities for preventive treatment. Carers also tended to seek help later, creating higher levels of stress and reduction quality of life.

Specific barriers to accessing service usage amongst Asians were:

- Lack of knowledge about dementia and services
- Cultural differences,
- Communication and language difficulties,
- Fear of breach of confidentiality
- Stigma
- Lack of knowledge among service providers and managers about the lifestyles, health, religious and cultural needs of Asian people

**Local Services**

Of course people of all ethnicities access all local services as outlined elsewhere in this report, however particular mention must be given to two particular services:

**Meri Yaadain**

Meri Yaadain (meaning My Memories) is a local initiative focused on addressing issues relating to dementia in Black and Minority Ethnic (BME) communities, and in particular the district’s large south Asian community. The work has become established as a long-term initiative working to raise awareness of dementia amongst the older South Asian communities in Bradford. Meri Yaadain set off to look at the needs amongst the South Asian communities, but we are now beginning to work across all BME communities.

Meri Yaadain is a Social Services (Adult Social Care) led initiative in partnership with Clinical Commissioning Groups, Age Concern Bradford and the Alzheimer’s Society in Bradford. The staff undertake a wide range of activities to reach out to and engage with older people who have dementia and their carers and families who need educating about the condition as well as the services available to help them.
The team deliver:

- **Community roadshows** – taking staff out to community centres to talk about dementia, services available, listen to carers’ concerns and feedback to service providers.
- **Quarterly newsletter** – this is produced in English to help get the dementia message across to the wider community as well as being available in 6 further languages
- **Radio programmes** – to help reach out to people who are house-bound or simply do not attend community centres and places of worship
- **Home visits** – to help carers have someone to talk to and get some information from. This is to help them feel supported and to help with signposting towards appropriate health and social care services
- **Support Group** – a monthly get together of like minded people, both carers and people suffering from dementia, enables sharing of information, some activities, relaxation and a bite to eat
- **Telephone advice** – for those who need a quick chat or have question. This often allows a quick referral onto an appropriate agency.
- **Work with schools** – to help students contribute to the work of Dementia in the Community.

To date, Meri Yaadain has supported approximately **220** individual and families, with a current caseload of about **80**.

**Bradford Dementia Roadshows**

Raising awareness about dementia within specifically identified BME communities, was the initial first step in improving access to dementia services and the inspiration for the 5 BME dementia awareness road shows. The identified communities were Indian, African and Caribbean, Central/Easter European and Irish. Funding was sought from Bradford Council Dementia Small Grants Fund.

The main aims of the roadshows were to:

1. Explain the terminology and language used around dementia
2. Improve understanding of dementia, and awareness of how to access services and the possible benefits of early diagnosis and care
3. Reduce fear and misunderstanding
4. Showcase support available to people with dementia and their carers.
The roadshows were open to persons with dementia, carers and members of the wider community, and were delivered at local community venues familiar to each BME group

- multiple-choice questions to which people responded using coloured voting cards
- talk about the nature of dementia by one of the steering group (Jan Oyebode/ Akhlak Rauf)
- live or videoed accounts of living with dementia, by people with dementia or carers from the relevant community
- Round table discussions

The roadshows were well attended, although results from the Irish community are not available (they are a small population (0.49% of the population in Bradford), and there has been some closure of Irish community services, with two day centres have been closed in the recent past). Numbers attending were:

Indian 62, African and Caribbean 50, East and Central European 63, Irish 2)

The results of the multiple choice questions are shown in table 1 below:

**Key observations include:**

- The Central and Eastern European community generally score most positively in terms of “correct” answers
- The Indian community generally score least positively in terms of “correct answers
- Conversely, the Indian community tended to see themselves as most knowledgeable about dementia generally
- A very small number of Indian people are aware of Wellbeing Cafes
- Only numbers of Indian people feel that there enough information in their community on dementia
- Only small proportion of the Indian and the African Caribbean communities are aware how to access social services support
### Table 1: Results of Bradford Dementia Roadshow Multiple Choice Questions

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<td>51</td>
<td>14.1%</td>
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**People with dementia have the same needs as young children?**

**Everyone who is old has a poor memory**

**Dementia begins with memory loss**

**How much do you know about dementia?**

**People with dementia usually become aggressive**

**Is there enough information in your community on dementia?**

**Are you aware of services for dementia?**

**Do you know what Wellbeing Cafes are?**

**Are you aware how to access social services support?**

**Could you recognise the symptoms of dementia?**

**Is there a Wellbeing Café in your area?**
Findings in this Report

Key findings elsewhere in this report in respect of dementia and ethnicity include:

• The majority of BME groups live primarily in the City area, and are less likely to live in urban areas

• Work carried out as part of the qualitative analysis (see Section 8) indicated that community based activity in the 3rd sector is structured around five generalized ethnic groups; White, South Asian, African/Caribbean, Central Eastern European and Irish

• There is a relative underrepresentation of people from the South Asian community in:
  o Memory Assessment and Treatment Services
  o Hospital Admissions

• Poor quality of ethnicity coding limits the applicability and robustness of local data

• Some South Asian people do not like being seen attending mental health services or follow up appointments for fear of stigmatisation

• Cultural attitudes to elders may be important in generating referrals

• Services should be culturally appropriate and staff culturally competent

• It was felt that across cultures there are diverse attitudes to carers and looking after elders.

• Cultural attitudes and norms in respect of dementia and mental illness may be preventing people from BME communities accessing dementia services

• South Asian families may be more reluctant to put elders into care

• The increased incidence and risk of cardiovascular disease and diabetes in South Asian people places them at an increased risk of developing vascular dementia

What does this mean for Bradford and Airedale?

Clearly Bradford and Airedale has a rich ethnic diversity, with high numbers of people from BME communities, particular the South Asian community. This raises particular concerns about the increased risk of vascular dementia in this community, analogous with the better understood increased risk of cardiovascular disease (this also applies to the Black African community). Clearly there is potential for primary and secondary prevention in the vascular dementia BME community.

This report demonstrates at a number of points the underutilisation of dementia services by South Asian people in Bradford and Airedale, it is important that this is investigated further in order to better understand the reasons for this and to identify any broader lessons that can be learned.
Dementia tends to occur at a younger age in South Asian people, primary care staff, particularly in the City area should be aware of this to inform their index of suspicion of dementia in younger people. The number/proportion of South Asian people living in the district is set to rise significantly to 2031 – this should be incorporated into strategic and operational planning

**Recommendations**

1. Work should be undertaken with academic partners to develop culturally appropriate and robust screening and evaluation tools
2. Work should be undertaken with both clinicians and the South Asian community to promote primary and secondary prevention of vascular dementia
3. Efforts should continue to improve coding of ethnicity across all services
4. The Dementia Strategy should explicitly take into account the rising number of people from BME communities across the district

**REFERENCES:**

4. All party Parliamentary Group on Dementia. Dementia does not discriminate - The experiences of black, Asian and minority ethnic communities. House of Commons 2013


