



All-Party
Parliamentary Group
on Dementia

Dementia does not discriminate

The experiences of black, Asian
and minority ethnic communities

July 2013



House of Commons
All-Party Parliamentary Group
on Dementia

Dementia does not discriminate

The experiences of black, Asian
and minority ethnic communities

July 2013

Contents

Foreword.....	5
1 All-Party Parliamentary Group on Dementia.....	7
1.1 Terms of reference for the inquiry.....	7
1.2 Working group.....	8
1.3 Acknowledgements.....	9
1.4 Enquiries.....	9
2 Summary and recommendations.....	10
2.1 Summary.....	10
2.2 Recommendations.....	12
3 Research to inform this report	15
4 Background and context	16
4.1 Dementia.....	16
4.2 Black and minority ethnic communities and dementia	17
4.3 Increased risk of dementia among BAME communities	18
4.4 Life history of people with dementia from BAME groups.....	19
4.5 Recognising diversity within ethnic groups	20
5 Community perspectives on the care of the elderly	21
6 Awareness and understanding of dementia among BAME communities....	24
6.1 Dementia as a health condition	24
6.2 Language	25
6.3 Myths and misconceptions about dementia.....	25
6.4 Stigma surrounding dementia.....	26
6.5 The impact of stigma and low levels of awareness	27
6.6 Social isolation	28
7 Access to services.....	30
7.1 Families and individuals may not seek support.....	30
7.2 Lack of culturally sensitive services.....	31

7.3 Opportunities for improving support.....	32
7.4 Understanding the needs and assets of the local community	34
Appendix 1: Race equality legislation.....	36
Appendix 2: Case studies	37
A2.1 Bradford Metropolitan District Council information support and advocacy service.....	37
A2.2 Family carer using direct payments.....	38
A2.3 Rochdale befriending service.....	38
A2.4 Royal Borough of Kingston upon Thames Admiral Nurse service	39
A2.5 Alzheimer’s Society Connecting Communities Project	40
A2.6 Dementia awareness sessions and a community dementia link worker training programme for a range of BAME communities in Gloucestershire	41
A2.7 Somali Mental Health Network (SMHN) and Bangladeshi Mental Health Network (BMHN) in Camden	43
References	44

Foreword

Today more than 800,000 people are living with dementia. By 2021 it will be more than a million. Dementia is the biggest health and social care challenge facing our society. Finally it feels that government, politicians and the wider public are beginning to confront that challenge and take action.

More people than ever before are now getting access to a diagnosis, are being given the right information to help them cope, and are receiving real person-centred care. But I regret that there are tens of thousands of people living with dementia every day who are not getting the services they are entitled to. And disproportionately it is people from black, Asian and minority ethnic (BAME) communities who are being failed by the system.

Since its inception, the All-Party Parliamentary Group (APPG) on Dementia has shone a light on aspects of dementia care that have been neglected by policy-makers.

We uncovered the shocking over-prescription of anti-psychotic drugs to people with dementia in care homes, that later resulted in a significant reduction in their use across all care settings. Last year we investigated the reasons why fewer than half of people with dementia were getting a diagnosis. We welcome the target, announced by the government in May 2013, that two thirds of people with dementia will be diagnosed by 2015.

This year the APPG investigated the experiences of people from BAME communities with dementia. As this report sets out, the number of individuals with dementia from these communities will increase rapidly in the coming decades.

Our inquiry heard about high-quality services that were tailored to support people with dementia from BAME communities. But we uncovered that these services are too few and far between, and many people struggle on with too little support from the NHS or local government.

This inquiry has established that there is an urgent need to increase awareness of dementia among BAME communities. Service providers need to be sensitive to cultural stereotypes that mean some communities are assumed to 'look after their own', resulting in services that do not reach out to individuals and families from BAME communities.

We make recommendations for the UK government, for local commissioners, and to others who must take action now. Such action is desperately needed not just across the public and voluntary sector, but in society as a whole, if we are really to ensure individuals and families are not left to cope alone, in fear, and without support.

I am determined that this report and its examples of good practice will help us move forward.

A handwritten signature in black ink, reading "Sally Greengross". The signature is written in a cursive style with a large initial 'S'.

Sally Greengross
Chair, All-Party Parliamentary Group on Dementia

1 All-Party Parliamentary Group on Dementia

The All-Party Parliamentary Group (APPG) on Dementia was formed in 2007 to build support for dementia to become a publicly stated health and social care priority, and therefore meet one of the greatest challenges presented by our ageing population.

Since the establishment of the group, dementia has been recognised by all political parties as a priority for government and policy-makers. Today the challenge is to translate that commitment into actions that will have a positive impact on the lives of people with dementia and their carers.

1.1 Terms of reference for the inquiry

In December 2012 the APPG on Dementia announced that it would undertake an inquiry into services and support for people living with dementia in the UK within minority ethnic groups.

Demographic profiling has identified the white Irish, Indian, Pakistani and black Caribbean communities as the largest ethnic minority communities in the UK. The area of the UK with the highest black, Asian and minority ethnic (BAME) population is Greater London, with significant Asian communities in the West Midlands, and the North West, extending into West Yorkshire. The number of people with dementia from BAME groups in the UK is increasing as people who moved here during the period from the 1950s to the 1970s are reaching their seventies and eighties.

Current evidence in this area is limited, but it does indicate there might be lower awareness, higher levels of stigma, and different cultural understandings of dementia among people from BAME communities. Research also suggests that people present later to general dementia services than their white British counterparts, when their dementia has become more severe.

This inquiry brings together evidence and understanding about the experience of people with dementia from BAME communities. It also sought good practice examples where services have been tailored to people with dementia from BAME communities, so that these examples can be shared. The inquiry explored the following questions:

- What are the factors, if any, which stop people from BAME communities seeking early help/intervention and/or getting a diagnosis? How can these factors be overcome?

- How can we improve diagnostic tools and the diagnostic experience for people from BAME communities?
- How do BAME individuals and families experience living with dementia?
- What services might BAME individuals and families be looking for?
- What are the best ways to reach BAME communities?
- What challenges might be encountered when developing and providing tailored services to people with dementia from minority groups? How can these be overcome?
- Which organisations and individuals, at local and national level, are best placed to lead this work?

The APPG on Dementia sought evidence from a wide range of people including people with dementia and their carers, health and social care providers and practitioners, and experts in dealing with those issues faced by people from different minority groups.

1.2 Working group

Members of the inquiry working group, who heard a summary of research findings and oral evidence from organisations and individuals on 19 and 21 March 2013, are as follows:

Baroness Sally Greengross (Chair)

Tracey Crouch MP

Debbie Abrahams MP

Lord Walton of Detchant

Oliver Colvile MP

Stephen Lloyd MP

Baroness Judith Jolly

Witnesses at oral evidence sessions:

- Alli Anthony, Alzheimer's Society
- Charlotte Curran, Federation of Irish Societies
- Chetna Shah, Enfield Asian Welfare Association
- Dr Jo Moriarty, Social Care Workforce Research Unit, King's College London
- Dr Mina Bobdey, Old Age Psychiatrist, Tees, Esk and Wear Valleys NHS Foundation Trust

- Dr Omar Khan, Runnymede Trust
- Kirit Nayee, carer
- Hamid Rehman, Ethnos Research and Consultancy
- Professor Rob Stewart, Institute of Psychiatry, King's College London

1.3 Acknowledgements

The group would like to thank Alzheimer's Society for its assistance in collating written evidence for the inquiry and organising the oral evidence sessions. We would like to thank Samantha Sharp, Senior Policy Officer at Alzheimer's Society, for writing the report along with Hamid Rehman and Radhika Howarth of Ethnos Research and Consultancy, and Nicola O'Brien, Public Affairs Adviser, for supporting and co-ordinating the inquiry.

We would also like to thank the witnesses who took part in the oral evidence sessions, as well as those individuals and organisations that submitted written evidence.

1.4 Enquiries

Please direct any comments or queries that you may have about this report or about the Group to the Secretariat at appg@alzheimers.org.uk. Alternatively, contact the Chair, Baroness Greengross, at the House of Lords, London, SW1A 0PA.

2 Summary and recommendations

2.1 Summary

The ageing BAME population needs support

The number of people with dementia from black, Asian and minority ethnic (BAME) groups is expected to rise significantly as the BAME population ages. The Centre for Policy on Ageing and the Runnymede Trust applied well established dementia prevalence rates to census data, giving a current estimate of nearly 25,000 people with dementia from BAME communities in England and Wales.* This number is expected to grow to nearly 50,000 by 2026 and over 172,000 people by 2051. This is nearly a seven-fold increase in 40 years. It compares to just over a two-fold increase in the numbers of people with dementia across the whole UK population in the same time period.

Society is not geared up to deal with this increase. Currently, people from BAME communities are under-represented in services and they are often diagnosed at a later stage of the illness, or not at all. Taking action now to get appropriate services and support in place will help to ensure people can access the support they need. Families will be better able to cope and individuals with dementia will be able to experience a better quality of life.

It is important to avoid assumptions that families from BAME communities do not require any outside help. Carers of people with dementia experience greater strain and distress than carers of other older people. The risk of stereotyping is a failure by services to reach out to BAME communities and ensure services are in place to support the wellbeing of carers and individuals with dementia.

It is likely that dementia is more common among Asian and Black Caribbean communities. This is because high blood pressure, diabetes, stroke and heart disease, which are risk factors for dementia, are more common among Asian and Black Caribbean communities. These are modifiable risk factors and preventative work is vital to reduce significantly the burden of dementia among BAME communities.

* This estimate includes all non-white groups and also the white Irish population. The white Irish community is one of the largest groups in the UK and has a significant proportion of older people. It may be possible and appropriate to include other communities from the 'White other' group in future estimates, as the number of older people in these groups increases. Data is not available for Northern Ireland or Scotland.

Improved awareness leads to improved access to services

Government public awareness campaigns to date have had limited impact on the BAME community. Evidence shows that knowledge and understanding about dementia in these communities is very low. There are myths and taboos attached to the condition. Although stigma is attached to dementia in all communities, it is likely that levels of stigma are higher in BAME communities.

The stigma and low levels of awareness surrounding dementia make it more difficult for people to get the support they need. Social isolation and delays in diagnosis are significant risks. Diagnosis can be a gateway to support, and enables people to plan for the future. It is unacceptable that people from BAME communities have poorer access to diagnosis and support.

Existing good practice should be disseminated

Service provision for people with dementia from BAME communities is patchy. Pockets of good practice exist, but in many areas there is lack of support that meets the needs of people from BAME communities. The Department of Health, local governments and the NHS are not ensuring that good practice is disseminated.

Families may not seek support because of a desire to care for the person within the family, but also community pressure to do so even when the burden of caring is considerable. There is also a lack of awareness of services, how they might help or how to access them. Previous experience of hostility and racism among some communities may also deter people from seeking help.

There is also felt to be a lack of culturally sensitive dementia services. Families are reluctant to use services that do not meet cultural or religious needs and try to carry on alone.

There is a large ethnic minority voluntary sector providing culturally appropriate support to older people, but its members may not be skilled in providing dementia care. Shared learning between these services and specialist dementia services would improve the support each could offer people with dementia from BAME communities.

There is a significant increase in the number of people with dementia from BAME communities and the evidence presented in this report shows low levels of awareness of dementia, late diagnosis and lack of access to culturally sensitive services. Therefore, we need action from a range of bodies to ensure every individual with dementia and their families can access the high-quality, person-centred support they need.

2.2 Recommendations

While the APPG represents people from across the UK at Parliament, health policy is devolved to the health department of each country's government. The recommendations in the report apply to either the NHS or health and social care systems in England, or to non-governmental bodies who have UK-wide jurisdiction. However, governments in Wales and Northern Ireland should address the issues highlighted within the report in their own countries and consider what could be learnt from the evidence presented and the resulting recommendations.

Recommendation 1: Raise awareness

- **Public Health England** should fund a pilot campaign that aims to raise awareness of dementia among BAME communities and, in doing so, to challenge the stigma surrounding the condition.
- The campaign should be informed by research that considers whether different BAME communities require a different approach. BAME community and faith groups should be involved in the design of the campaign.
- A targeted campaign to raise awareness and understanding of dementia aimed at schools and young people should form part of any awareness campaigning, given the important role young people play in changing community attitudes.
- Organisations representing people with dementia and their carers, as well as ethnic minority community groups, should work with specialist BAME media in order to raise awareness of dementia among BAME groups through print and broadcast media channels.

Recommendation 2: Undertake preventative work and tackle modifiable risk factors

- **Public Health England** should lead a specific programme of work to reduce the burden of dementia among people from Asian and African-Caribbean groups by targeting the preventable risk factors that are more prevalent within these communities.
- **Clinical commissioning groups** with high numbers of older people from BAME groups should develop effective joint working practices between stroke services and dementia services. These could provide a model for good ways of working at a national level.

Recommendation 3: Ensure local areas are aware of the need to support people with dementia from BAME groups in their communities

- **Local authorities and clinical commissioning groups** should ensure that the Joint Strategic Needs Assessment (JSNA) includes information on the numbers of people from BAME communities, their age profile and the resulting estimates of people with dementia.
- The JSNA should assess the adequacy of services available to support people with dementia from BAME communities and address gaps. As part of this, the JSNA should appraise the assets already available in the community, for example ethnic minority community groups as well as dementia services, and consider whether it would be appropriate to provide additional support to these groups in order to meet the needs of individuals with dementia from BAME communities.
- Doing so would help to fulfil the public sector duty to advance equality of opportunity within their local areas.

Recommendation 4: Share good practice in commissioning and support

- **The Department of Health** should commission work mapping specific services for people with dementia from BAME communities across England. This should form the basis of a project to share best practice and develop expert commissioning guidance for local areas.
- **The Social Care Institute for Excellence (SCIE)** should act as a hub for an online library of good practice in support for BAME people with dementia.

Recommendation 5: Improve access to high-quality services for people with dementia from BAME communities

- **Health and wellbeing boards (HWBs)** should encourage local joint working between BAME community groups and dementia services from the health, social care and voluntary sectors. HWBs should facilitate forums for sharing expertise between these groups to improve the ability/confidence of mainstream dementia services to deliver culturally sensitive services and enable community groups to better support people with dementia.
- These forums should include representatives from housing associations, domiciliary care providers and care homes, to ensure they provide people with dementia from BAME communities with good support.

- **The Care Quality Commission (CQC)** should consider as part of its inspection work whether a service is equipped to provide good care to people with dementia from BAME groups.
- **Local Healthwatch** should ensure they are accessible to BAME communities. This includes ensuring written information is available in a range of languages and BAME communities are aware of Healthwatch's service and how to access it.
- **Organisations providing services to people with dementia and their carers** should develop specific services to support people with dementia from BAME communities. These could include dementia cafes, befriending services and dementia advisers.
- **Organisations providing services to people with dementia and their carers and/or advocating on their behalf** should actively reach out to diverse audiences when advertising employment and volunteering opportunities, and should review recruitment practices to ensure all applicants are treated fairly.

Recommendation 6: Alzheimer's Society programmes

- **Alzheimer's Society** should encourage the take-up of the Dementia Friends programme among BAME groups. In particular, it should increase the numbers of Dementia Champions from BAME groups.
- **The Alzheimer's Society Dementia Roadshow** should visit areas with large BAME populations and ensure its services are appropriate and accessible to BAME communities.
- **Learning from dementia-friendly communities** with large BAME populations about how to support the wellbeing of people with dementia from minority ethnic groups should be shared across other dementia-friendly communities.
- **Building on the knowledge gained through the Connecting Communities project**, Alzheimer's Society should initiate outreach to establish the needs of a broad diversity of groups across the UK.

Recommendation 7: Improve staff knowledge and skills

- **Training bodies** for staff involved in the care and support of people with dementia, including Health Education England, the Royal College of Nursing, Skills for Care, Skills for Health, the Royal College of Psychiatrists and the Royal College of Physicians, should ensure their training programmes include the topic of culturally sensitive care.
- **The Royal College of General Practitioners** should develop guidance on improving diagnosis rates among black, Asian and minority ethnic people thought to have dementia.

3 Research to inform this report

As well as the oral evidence sessions, the APPG commissioned Ethnos Research and Consultancy, a company specialising in research with ethnic minority communities, to research the needs of various communities with respect to dementia. The anonymised quotes within this report are taken from this research.

The aims of the research were to identify:

- knowledge, attitudes and behaviour concerning dementia
- ways in which people experience living with dementia
- barriers to people seeking early support for dementia
- service requirements of people with dementia and their carers
- challenges in developing services for people with dementia.

The research was conducted with five BAME communities: Irish, Indian, Pakistani, Black Caribbean and Chinese. These communities were selected based on three criteria:

- These are some of the largest groups in terms of population size.
- They have been in the UK for a significant period of time resulting in a significant proportion of elderly people.
- They have distinct cultural and religious practices that are likely to affect their knowledge, attitudes and behaviour towards dementia.

It is important to state that, as a non-visible minority, the needs of the Irish community are often overlooked by policy-makers and service providers. They are not considered to belong to an ethnic minority. As a consequence, their needs are assumed to be similar to the white British majority, with no effort made to identify their specific needs or to make special provision to meet those needs. This study found the Irish in Britain to have distinct traditions and cultural practices that have a profound bearing on the needs of Irish people with dementia. Their cultural needs are not dissimilar to the needs identified for the other BAME groups in the study.

Please email appg@alzheimers.org.uk for more details of the research methodology used.

4 Background and context

We have to tell our community that there is nothing to be ashamed of.
We need to develop the right services and tell people about them.

(Asian service provider, Ethnos research)

4.1 Dementia

The term ‘dementia’ describes a set of symptoms that include loss of memory, mood changes, and problems with communication and reasoning. The most common types of dementia are Alzheimer’s disease and vascular dementia. Dementia is progressive, which means that people with dementia and their carers are coping with changing abilities over time. Eventually people with dementia will need help with all their daily activities.

There are around 800,000 people in the UK with dementia and an estimated 670,000 people in the UK who act as primary carers for people with dementia. Carers save the state £8 billion per year in care and support costs (Alzheimer’s Society, 2012a). The numbers of people with dementia and the associated costs to the state and families are expected rise significantly as the UK population ages.

Evidence of the growing burden of dementia has led to the development of a range of public policy initiatives. Reports highlighting failings in the provision of support to people with dementia and their carers were also a stimulus for action (NAO, 2007, 2010). National dementia strategies in England, Wales and Northern Ireland have been produced to try to ensure the needs of people with dementia are properly addressed in years to come. The Prime Minister’s Dementia Challenge was published in March 2012 to build on the National Dementia Strategy for England (Department of Health, 2012). The main areas for action in the challenge are driving improvements in health and care, creating dementia-friendly communities and improving dementia research.

The All-Party Parliamentary Group welcomes the ongoing focus on dementia, particularly given the slow progress in some areas. The need to improve rates of diagnosis is a particular sticking point. This was the subject of the 2012 APPG inquiry ‘Unlocking diagnosis’ (APPG on Dementia, 2012). Across England, Wales and Northern Ireland only 44 per cent of people living with dementia have a diagnosis (Alzheimer’s Society, 2013). This figure masks considerable variation. Diagnosis rates range from 31.6 per cent in East Riding of Yorkshire to 75.5 per cent in Belfast. In response to this, NHS England (NHSE) has set a national ambition for England that two thirds of people with dementia should have a diagnosis, as well as ongoing support.

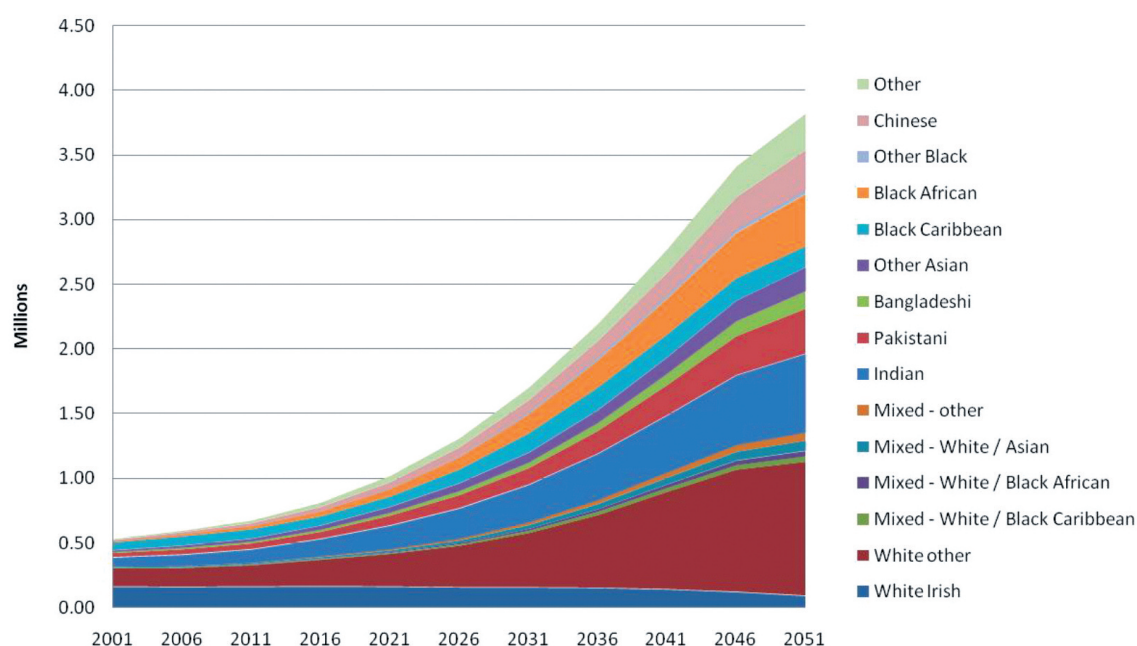
4.2 Black and minority ethnic communities and dementia

Previously it has been estimated that there are 11,392 people with dementia from BAME groups (Knapp et al, 2007). In order to understand the expected growth, the Centre for Policy on Ageing and the Runnymede Trust applied well established dementia prevalence rates to census data and projections based on census data. This gives a current estimate of nearly 25,000 people with dementia from BAME communities in England and Wales.* This number is expected to grow to nearly 50,000 by 2026 and over 172,000 people by 2051. This is nearly a seven-fold increase in 40 years. This compares to just over a two-fold increase in the numbers of people with dementia across the whole UK population in the same time period.

The huge growth in numbers of people with dementia from BAME communities is to be expected as the UK BAME population ages. In 2001 there were about 532,000 people from BAME groups aged 65 and over; by 2051 there will be 3.8 million (Lievesley, 2010). Figure 1 demonstrates the growth in BAME elders.

Previous research published by SCIE has found that people from BAME groups are under-represented in dementia services (Moriarty, Sharif and Robinson, 2011). They are also less likely to receive a diagnosis or are diagnosed at a more advanced stage

Figure 1: The ethnic minority population of England and Wales aged 65 and over



Source: Lievesley, N (2010). The future ageing of the ethnic minority population of England and Wales. London: Runnymede Trust

* Data is not available for Northern Ireland or Scotland.

of illness than white British people (Moriarty, Sharif and Robinson, 2011). These challenges are likely to affect the wellbeing of people with dementia, place unacceptable strain on families and increase the risk of avoidable crises and need for intensive, high-cost interventions.

The expected huge growth in the number of people with dementia from BAME communities demands urgent action to address the low rates of diagnosis and uptake of services. As recognised by the national dementia strategies, carefully planned strategies to establish support systems can help avert crises and enable services to cope with increasing demand. It is vital to understand the needs of individuals with dementia from BAME communities in order to get the right support in place over the coming years.

4.3 Increased risk of dementia among BAME communities

Although no data is currently available on incidence of dementia in 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 risk factors for dementia, are more common in these communities.

During oral evidence sessions, Professor Rob Stewart explained that:

African Caribbean populations have about double the risk of stroke compared to similarly-aged European-origin people, as well as high levels of hypertension and diabetes. This is also true for South Asians, who also have a high level of diabetes and have a raised risk of stroke, although not quite as high as African Caribbean populations.

Professor Stewart explained the implications. First, it is only now that UK BAME populations are reaching ages where dementia becomes common and where these increased risk factors will have an impact. The resulting increase in numbers of people with dementia from ethnic minority communities creates an urgent need to address the current under-diagnosis and failure to provide appropriate services highlighted by others giving oral evidence.

Second, services to assess and treat dementia and comorbidities associated with this must be well integrated. Alzheimer's Society work has already highlighted that stroke professionals are good at treating physical symptoms and giving secondary preventative advice. However, although monitoring of cognitive problems has improved, this could still be more robust. Many people who have a stroke will receive good services in relation to physical symptoms but will receive little information and support in relation to cognitive impairment. Individuals who go on to develop dementia after a stroke may not receive a diagnosis or necessary support.

Equally, mental health teams assessing someone with dementia associated with major or minor strokes may lack the knowledge and skills to treat underlying physical disorders or offer the appropriate rehabilitative support which could improve independence and wellbeing. Treatment of vascular risk factors, which may be contributing to the progression of the dementia, is not optimal at the secondary care level.

Third, Professor Stewart highlighted that the risk factors for stroke and dementia that are more common among BAME groups may be prevented and/or treated – for example, reducing high blood pressure and preventing obesity and diabetes. Therefore, services that aim to reduce these risk factors are very important and have the potential to reduce significantly the burden of dementia among BAME communities.

For the younger generations coming up there is ample opportunity to try to prevent diabetes, treat diabetes, keep blood pressure under control and prevent problems with high cholesterol. There is ample opportunity to try to intervene to reduce the future risk of dementia in these communities.

4.4 Life history of people with dementia from BAME groups

Many of the challenges faced by people with dementia and their carers from BAME groups are similar to those faced by the white British population. These include stigma surrounding dementia and difficulty accessing support from statutory services. However, some of the causes of these challenges are specific to BAME groups and therefore require a different response. It is also important to consider the life history of people from BAME groups and how this will affect their experience of dementia. During the oral evidence sessions, Omar Khan pointed out:

If you are 65 today you were born in 1948. Obviously Windrush, which is the first period of post-war large-scale migration to the UK from ethnic minority populations, happened in 1948... So most of the people who are presently over 65 are overseas-born, and I think that raises a distinctive set of issues for the current older ethnic minority population.

As the symptoms of dementia develop and individuals begin to lose their short-term memories, longer-term memories may come more to the fore. This may be distressing for people who migrated to the UK during the mid-twentieth century and experienced hostility and racism. It will also make reminiscence work, which can be therapeutic for many people with dementia, very difficult as it may stir up memories of a difficult period in people's lives.

Some individuals may also revert back to their native language. During the oral evidence session, Charlotte Curran also pointed out that with many people migrating when they were young men or women, they may have no experience of dementia within older generations or model of how to cope. Services for people with dementia from BAME groups will need to understand and respond to these issues.

As Dr Karan Juttla (Senior Lecturer, Association for Dementia Studies, University of Worcester) pointed out during the oral evidence sessions, understanding and responding to the unique life history of individuals is part of person-centred care, which is the essence of good dementia care. Person-centred care means valuing each individual and their unique personality, culture, life history and preferences. Staff providing person-centred care treat individuals with dementia with dignity and respect and consider situations from the perspective of the person with dementia.

4.5 Recognising diversity within ethnic groups

There has been concern that using the term ‘black, Asian and minority ethnic communities’ risks ‘a blanket policy and practise response that doesn’t take diverse individual needs into account’ (Butt, 2006, p2). Furthermore, the SCIE research briefing on black and minority ethnic people with dementia notes the ‘immense variety to be found among BME populations in the UK, coining the term “super diversity” to illustrate increasing diversity in aspects such as country of origin, socio-economic status, religious and cultural traditions and legal status’ (Moriarty, Sharif and Robinson, 2011, p2). Rauf (2011) uses the term ‘communities within communities’ to explain the range of beliefs, language and cultural norms and practices found within particular groups.

The APPG feels the term ‘black, Asian and minority ethnic communities’ is useful in this context as it focuses attention on groups that share a similar experience and face particular challenges in getting the support they need. But nonetheless it is important to acknowledge and respond to the differences within ethnic groups and, at an individual level, ensure a person-centred approach is taken.

5 Community perspectives on the care of the elderly

Research carried out by Ethnos for this inquiry explored community perspectives on care of the elderly in general in order to create a helpful context in which to understand black, Asian and minority ethnic (BAME) perspectives on dementia. Previous research has identified assumptions that families will 'look after their own' (Social Services Inspectorate, 1998). The risk of this stereotyping is a failure by services to reach out to BAME communities and ensure support is in place.

Interviews carried out by Ethnos found that, at a personal and emotional level, most people would like to care for their elderly family members. However, among the Black Caribbean and Irish communities there is recognition that this is not always possible. There is an acceptance that family and work commitments, together with financial constraints, mean that families are often not able to look after elderly people themselves. Some continue to look after elderly family members at home, while others provide care from a distance, with regular visits or phone calls. There were, in these two ethnic minority communities, no cultural expectations or any community pressure that children should look after their parents.

For the most part the Irish community will see it as their duty to look after their elders. Daughters, wives and husbands are resistant to the thought of residential care. However, you wouldn't be classed as abandoning your elders if you were forced to resort to residential care. The pressure is internal. It's in your heart. This is compounded by the fact that residential care does not meet the cultural needs of the Irish people.

(Irish service provider)

Among the Indian, Chinese and Pakistani communities there is a strong cultural tradition that children will look after their elders, and, importantly, that they will look after them in their own homes. This puts a lot of pressure on many children.

I do feel the pressure. If I said to my father, 'I want you to go into a home,' he would be very upset and I would be made to feel guilty. And the Chinese community would think I am heartless. They would say you are neglecting your parents.

(Chinese carer)

However, interviews with Chinese and Indian service providers and carers suggest that this situation may be changing among these communities. Some are now accepting that caring for their elderly relatives may not be practical in this country any longer.

My son lives in Buckinghamshire. He has his own family and can't live with us. He is very nice and caring and comes with us to all hospital appointments.

(Indian carer)

People come from villages outside Hong Kong, Taiwan or Malaysia. Back home everyone lived in one big house. But here that is not possible. If you have started your own family then it's hard to support older people.

(Chinese service provider)

Service providers working with the Indian community suggest that, although the extended family unit is still very close, more and more elderly parents are living on their own. A service provider working with the Indian community stated that almost 70 per cent of the elderly Indian clients attending the Asian elderly day centre were living on their own.

Among Pakistani people there continues to be a strong tradition that children will look after their parents and live with them. The onus of looking after elderly parents often falls on the son and, if he is married, his wife.

Never in residential care. Not done in our community. How can you think about doing this when their children are still alive?

(Pakistani carer)

My mother is elderly. She doesn't like any outsiders helping with personal care. My wife does everything for her.

(Pakistani carer)

Service providers working with the Pakistani community state that there is a practice among Pakistani parents of finding a bride for their sons from Pakistan, with an expectation that she will be duty bound and adhere to the traditional norms of caring for her in-laws. One cynical viewpoint was:

I know in these communities they are still marrying and bringing daughter-in-laws who are cheap carers; free carers.

(Asian service provider)

Although many people take pride in caring for a family member with dementia, the burden of caring for a person with dementia can be considerable. Carers of people with dementia experience greater strain and distress than carers of other older people. When carers are well supported, they provide better care to the person they care for (Ablitt, Jones and Muers, 2009). Pressure to carry on caring even when under considerable strain risks the wellbeing of the carer as well as the person with dementia.

6 Awareness and understanding of dementia among BAME communities

My mother still refuses to accept that my father has dementia. She refuses to understand his condition and asks me the same questions about why he is behaving the way he is. I have tried explaining to her so many times. It's the cultural thing.

(Pakistani carer, Ethnos research)

Moriarty, Sharif and Robinson (2011, p5) concluded that 'there is considerable evidence suggesting lower levels of awareness among BAME groups of the causes of dementia and the way that it affects people's lives.' Ethnos' research also found the level of awareness and understanding of dementia, even among the younger carers, was minimal. Raising awareness of dementia is an important first step to ensuring people with dementia and their carers get the support they need.

6.1 Dementia as a health condition

Most respondents associated the condition with 'getting old' or mental illness. Carers interviewed as part of the Ethnos research recalled seeing grandparents and other older people acting oddly and associated this with old age. When it became more severe it was assumed the person was 'going mad'.

I remember my grandma use to forget things. We thought it was just 'cause she was old. I now think it was dementia.

(Irish person with memory loss, Ethnos research)

We had no idea about this condition.

(Indian carer, Ethnos research)

This disease actually never existed in our community. Nobody would think that this is a health problem. People in my community would say that the person has gone mad or lost his mind.

(Pakistani carer, Ethnos research)

Sometimes, the symptoms of dementia are thought to be linked to another illness or to be a side-effect of medication, rather than caused by a specific condition.

My husband has diabetes and other health problems. I thought that this was some reaction or side-effect of the medicines he was taking for his other problems.

(Indian carer, Ethnos research)

Dr Mina Bobdey explained during the oral evidence sessions that there was no concept of cognitive impairment among some BAME families and this could lead to negative responses to a person with dementia. She said ‘many of the population feel that the elderly are putting it on because they need attention from the family.’

6.2 Language

There is no term for dementia in South Asian languages. It is often referred to in terms such as ‘not being able to remember things’, ‘being forgetful’ or ‘losing memory’. Among the Chinese there was a way of describing dementia, but the description was very derogatory.

The Chinese word for dementia is really bad. It’s like ‘crazy’ or ‘100 per cent docile’ or ‘nutty’. The term is used in an insulting way. It’s very negative.

(Chinese service provider, Ethnos research)

Rauf (2011) points out that people from the South Asian groups also struggle with the concept of ‘carers’.

6.3 Myths and misconceptions about dementia

Research suggests that there are a number of myths circulating about dementia among some BAME communities. This is largely to do with the association of dementia with mental illness. Some Black Caribbean people assumed that the mental illness was a result of a person being possessed by evil spirits. In the case of the Pakistani community, it was a result of possession by ‘Jinns’.

I often hear in my community that somebody has done something to her like cast an evil spell.

(Black Caribbean service provider, Ethnos research)

Alzheimer’s Society’s Living with Dementia magazine reported the experience of Dr Shafi Patoli, a coroner of Pakistani origin (Alzheimer’s Society, 2012b). His wife developed early-onset dementia. Some members of their extended family asked why his wife was seeing doctors and professors and not getting spiritual treatment. They said he should get his wife exorcised.

Some Black Caribbean and Asian respondents viewed dementia as a ‘white person’s disease’, because they had not come across the condition in their country of origin. They believed that people in their community got this disease as a result of coming to the UK.

Service providers interviewed by Ethnos suggest this view is most prevalent among the older age groups in the Pakistani and Black Caribbean communities.

A lot of people say to me this doesn’t happen in the Caribbean. It is only since we have come here to this country that you hear about such mental problems.

(Black Caribbean service provider)

Chinese service providers suggest that the Chinese have a strong belief in retribution for bad behaviour. They believe that if you do bad things then something bad will happen to you, or your children, or even your grandchildren. Serious health problems are assumed to be retribution for past bad deeds.

There are a lot of myths among the Chinese about health. They think that if you have cancer or a brain tumour or mental illness that it will be passed onto your children or grandchildren. Before a couple get married people delve into their health to find out if they have any such problems.

(Chinese service provider, Ethnos research)

6.4 Stigma surrounding dementia

These myths create considerable stigma around dementia, which may be higher than the stigma that still exists among the white British population (Moriarty, Sharif and Robinson, 2011). During the oral evidence sessions, Kirit Nayee explained his experience as a Hindu carer, whose mother developed dementia:

People find it hard; basically, they do not want the public to know. There are a lot of concerns within our religion and culture. Dementia: you know most people think it is not a disease, it is a thing people call ‘bonkers’ and all that kind of stuff. So it has a stigma attached to it. People tend to hide away from facing the facts, that there are real issues to be dealt with...

There was a consensus that the BAME media could play an important role in overcoming some of these misconceptions and increasing understanding of dementia. Over the last 10 years or so, discussion of dementia in the generalist UK media has certainly increased. The experiences of high-profile people who developed dementia have been reported and a number of soap opera characters have

developed dementia, thus bringing the subject into the homes of many people. During the oral evidence sessions, Chetna Shah of the Enfield Asian Welfare Association explained that one Asian soap opera included a character with dementia, but witnesses felt much more could be done to raise awareness of dementia through the BAME media.

Obviously for people who do not read or write in English, they do not watch the main terrestrial channels, they do not read the main newspapers. So obviously a lot of stuff there about people like Terry Pratchett and Iris Murdoch does not go out to them.

(Dr Jo Moriarty, oral evidence sessions)

6.5 The impact of stigma and low levels of awareness

The low levels of awareness and stigma surrounding dementia make it more difficult for people to get the support they need. Delays in diagnosis and accessing services are significant risks.

Individuals and their families are unlikely to recognise the early symptoms of the condition or perceive them as a health problem. Many carers reported being confused and uncertain about what to do when the behaviour persisted or the severity increased. It may only be once a person's symptoms become very severe that a family takes action.

People only take action when the conditions get worse and they are in the deep end. This is even with the second generation. Nobody will talk about it until the condition is clinical.

(Asian service provider, Ethnos research)

People accept certain behaviour as part of the ageing process. It is only when somebody becomes a danger to themselves or to somebody else that people actually take action.

(Irish service provider, Ethnos research)

When families do approach the GP with concerns about the person, the lack of a concept of cognitive impairment or dementia can make it difficult to provide a coherent account of symptoms. This creates another barrier to diagnosis.

Worryingly, some respondents report that some GPs stereotype people from certain groups. Irish are seen as 'drinkers', Asians as 'whingers'. Such stereotypes result in some people not seeing their GPs, while the symptoms of those that do are often not taken seriously.

We are finding that a lot of GPs have a stereotypical understanding of Irish people. They ask standard questions about alcohol, mental health and things they associate with Irish people. So people either don't tell the doctor, or when they do they are not understood or are stereotyped.

(Irish service provider, Ethnos research)

The APPG's 2012 inquiry 'Unlocking diagnosis' reviewed the benefits of receiving a diagnosis once a person has developed dementia (APPG on Dementia, 2012). Diagnosis gives a person access to treatment and, often, support services. It allows them to plan for their future. It provides individuals with knowledge of what is happening to them. Early diagnosis can also be cost effective, as reported by the Department of Health (DH, 2009). So addressing low rates of diagnosis among BAME communities is vital. During the oral evidence sessions, Jo Moriarty explained the inequalities that can result from late diagnosis:

If people are late in accessing a diagnosis then perhaps they no longer have capacity, it is very difficult for them to do things like financial planning, set up a power of attorney and make statements about where and how they would like to be cared for.

6.6 Social isolation

Myths and stigma associated with dementia can result in many people affected by the condition isolating themselves from their own communities. This is particularly the case for Chinese and Pakistani people, for whom community pressures are profound.

If someone has dementia the family will become very isolated. Only the very close family members will know about it. They will hide it from other family members or friends.

(Chinese service provider, Ethnos research)

I haven't seen anyone with dementia in my community. No one talks about it. It is hidden.

(Pakistani carer, Ethnos research)

Participants in the Ethnos research report how their social network slowly distances themselves from the person with dementia, because they find it difficult to cope with the person's changing behaviour. This is something that affects white British people as well as BAME communities, as it relates to social discomfort rather than any cultural factors.

Nobody rings her or comes to meet her. Her friends used to come and see her but have stopped now because they can't relate to her. They don't understand her behaviour. She will be speaking OK for a few minutes and then she will be repeating things over and over again. People don't want to meet her now.

(Black Caribbean carer, Ethnos research)

They are also saying that even within our own Irish community, when they go to Irish social clubs and they bring their elders, their behaviours can actually cause them to have anxiety and they are reluctant to bring them.

(Charlotte Curran, oral evidence)

As well as the stigma and taboos surrounding dementia, assumptions that BAME families always 'look after their own' can increase the likelihood of social isolation. Becoming isolated from the community removes potential sources of practical and emotional support for families living with dementia. It also compounds the lack of awareness of dementia among that community.

Certainly the research that has been done among carers from different ethnic groups particularly suggests that they often feel very isolated. They do not have other family members who will come in; they often are the sole carer, and they do not have this huge network of people who will take over for them very regularly.

(Jo Moriarty, oral evidence)

Raising awareness of dementia has been a key part of the national dementia strategies. Clearly there is much more to be done in this area among BAME groups to ensure equality of access to diagnosis and support. As well as raising awareness of the condition, work is required to inform BAME groups about the availability of services, how to access support and the benefits services can offer.

7 Access to services

People with dementia from BAME communities are under-represented in support services (Moriarty, Sharif and Robinson, 2011). There is likely to be a range of factors behind this. Evidence presented to the APPG suggests that individuals and families may not seek support from services, but also that suitable services are not available. While some families are equipped and happy to cope without outside services, a lack of support can result in huge pressure on carers. It can have a detrimental effect on the person with dementia if carers are struggling to cope.

7.1 Families and individuals may not seek support

The reasons individuals and families may not seek support include a desire to care for the person within the family, but also community pressure to do so even when the burden of caring is considerable. This is particularly the case with regard to residential care.

In our culture we don't like to take help. We are capable of looking after our parents at home. We need practical support.

(Pakistani carer, Ethnos research)

There is also a lack of awareness of availability of services, how they might help or how to access them. Also, the stigma that surrounds dementia in some BAME communities deters people from using services that are associated with the condition.

The hostility and racism faced by many migrants to the UK can also be a deterrent to seeking support from the state. Charlotte Curran explained that a sense of insularity has developed among Irish people following the difficult experience of migrating to the UK and this has led to a reluctance to seek help.

Gender roles can also play a part in how some BAME communities interact with statutory services. Rauf (2011, p3) points out that:

The women of the household are usually the carers within the families (not too dissimilar to white British families) but they may not have the same authority to influence or veto decisions made by the men. This creates a situation where a carer might be struggling to cope with caring whilst they may not be able to convince of the need for support. Equally too, it may be that the male family member seeks support services, but

the female carer feels it is a discredit to her if she is not able to carry out her duties as a wife, a daughter or a daughter in law.

Although women from BAME communities are more likely to go out to work now, research suggests women may be less likely to speak English which can be a barrier to accessing the support they need (Rauf, 2011).

7.2 Lack of culturally sensitive services

In addition to people not seeking out services, there is generally felt to be a lack of culturally sensitive dementia services. Often people feel that the support available is not appropriate and does not address needs relating to faith or culture. Families are reluctant to use these services and try to carry on alone.

We just sat there on our own all day; other people were dancing and singing. We had a cup of tea and in the evening they dropped us home. There was no one there we could talk to. There were all English people there.

(Indian carer, Ethnos research)

I felt lonely. There was no one to talk to. They spoke a different language.

(Indian person with memory loss, Ethnos research)

She was in tears every day...She was left in a rest room all day. There was no one to talk to her. All the staff and users were white. She felt like a cabbage. She had to conform to the food they served. She was not getting the food that she wanted. They didn't have halal or vegetarian food, so she started losing weight. I would give lots of biscuits and fruit from home, but she was not getting her own food.

(Black Caribbean carer, Ethnos research)

People from BAME groups may be particularly reluctant to attend support groups, where people can share experiences and gain support. 'Talking therapies' are not part of many cultures. Also the taboos associated with dementia mean people are reluctant to admit publicly that someone in their family has the condition.

I don't want to sit with a group of strangers and talk about my problems. I prefer to go to the ladies group in my mosque and just have a chat. This is my respite.

(Pakistani carer)

However, service providers suggested that, where such groups exist for people from BAME groups, they do participate in them. It would seem that although there may be initial reluctance to participate in such groups, once people have had this experience they do benefit from them.

Language barriers that exist between care staff and people with dementia can also create difficulties. During oral evidence Kirit Nayee explained that it makes it difficult to build a good relationship and level of trust:

Finding domiciliary carers in Crawley who speak Gujarati and the local language – the Gujarati language itself – and also is very culturally sensitive to her needs is very, very difficult. She would not even trust the carers who would come, because she does not understand; she would not be able to explain herself. So obviously we have been the main carers.

Some families had come across unhelpful assumptions among staff that BAME communities will not seek outside help:

I finally decided to call the social worker for help. She asked me why I didn't have family to help because Indian people always have relatives. She asked me so many questions that I felt guilty and put the phone down.

(Indian carer, Ethnos research)

7.3 Opportunities for improving support

There is a large ethnic minority voluntary sector, providing health and welfare support in a culturally relevant manner. Very few of its organisations provide dementia-specific services. However, because of the lack of culturally specific dementia services, many older people from BAME communities prefer to use generic care services tailored to their ethnic group.

Witnesses discussed the benefits of links between ethnic minority community groups and local specialist dementia services. Specialist dementia staff can offer training to ethnic minority groups to enable them to offer high-quality support to people with dementia. The Admiral Nurse service (Appendix A2.4) worked with a local ethnic minority community service and supported them to create a dementia resource pack to improve their understanding and skills in supporting people with dementia.

There are also specialist ethnic minority dementia services, but these are relatively few and far between. Jo Moriarty also explained that the funding for these services can be precarious:

There is a particular barrier in that innovative services are set up. They are often set up on initial funding for, say, three years and then they are unable to enter into the mainstream.

Two examples of specialist ethnic minority dementia services include the Rochdale befriending service and Meri Yaadain Dementia Team in Bradford (see Appendices A2.1 and A2.3).

It is also important that generic dementia services are able to offer support that responds to people's cultural and religious needs. Witnesses had a range of ideas for how this could be achieved.

The issue of culturally matching care staff with service users was discussed. This can be beneficial, but it was pointed out that it was not an essential component of good care for people with dementia from BAME groups. Omar Khan explained that staff matching can be inappropriate because 'if you have issues of stigma within the community, where people would rather not have someone from their own community in their own home because there might be gossip.' He advocates that decisions about culturally matching staff should be made on a case-by-case basis.

Equipping staff with the skills to understand and respond to people's individual cultural needs would help them provide good care to people regardless of their background. Karan Juttla of the University of Worcester pointed out at the oral evidence sessions that many staff lack confidence to provide care to people with dementia from different ethnic backgrounds. They may assume it is something they cannot do. But lack of confidence can be overcome through training that emphasises understanding cultural, social and political influences on people's lives as part of their individual needs.

It was also acknowledged that small changes to a service can make it much more acceptable for people from BAME communities. For example, staff could learn a few words of a person's language, which would enable communication and also make the individual with dementia feel more at home. Omar Khan suggested that care homes could order in food from local restaurants once a week:

I think people were pragmatic and they recognised it would be quite difficult if there was not significant demand, especially in a local area, to have a complete home dedicated to one community and people did not necessarily want that. They did want to interact with other communities, but they really wanted to make sure that their legitimate health and social care needs were met. So they talked about maybe one or two days a week having Chinese food. We think more could be done with local restaurants to think about partnering with care homes to provide that food for those older populations.

Links between local community groups and dementia services are also essential to support dementia services in providing good person-centred care that is tailored to a person's cultural needs. Alzheimer's Society Connecting Communities project is working closely with community leaders, people with dementia and family carers to ensure the awareness-raising material they produce is meaningful and appropriate for diverse communities. They are also consulting on the best approaches to use to raise awareness and the correct terminology (Appendix A2.5).

It was acknowledged that while there are areas with high concentrations of people from BAME communities, some communities are much more dispersed and some people can be isolated from other members of their ethnic group. Alli Anthony pointed out that training staff from generic dementia services was particularly important in these cases.

Also, Kirit Nayee explained that Hindu people living in rural or isolated communities 'will have an affiliation with a Hindu temple or the Hindu community centres and so on. Basically, you can actually communicate to everyone from that culture, including the rural ones.'

7.4 Understanding the needs and assets of the local community

It was highlighted that local areas need to understand properly the needs of their local community in order to get the right support in place. There may be assumptions in some areas that there would be no demand for culturally sensitive dementia services. However, the growing numbers of people with dementia from ethnic minorities and the increasing dispersal of older people from BAME groups mean all areas need to be aware of local need. Omar Khan pointed out that:

There are now only two local authorities in all of England that have fewer than 800 ethnic minority people living in them, whereas before there were many local authorities that had fewer than 100 ethnic minority people living in them, as recently as 2001.

The Joint Strategic Needs Assessment (JSNA) was seen as the key tool for understanding need. Charlotte Curran of the Federation of Irish Societies explained that they had found the JSNA was not being used effectively to understand need:

We carried out a snapshot analysis last year of JSNA. The Irish health needs are not being analysed. Although we are being recognised under demographics, there is no analysis of our health needs.

As well as understanding local need, local authorities should be looking at what assets they have within their communities that could be used to support people with dementia from ethnic minorities. This would include ethnic minority community groups as well as dementia-specific health, social care and voluntary sector services. Once assets are identified, work could be done on making links between them, to enable the sharing of expertise.

Appendix 1: Race equality legislation

Legislation is clear that individuals must not be discriminated against on the basis of their race.

Equality requirements in England, Scotland and Wales are governed by the Equality Act 2010. The Act protects people from direct and indirect discrimination in the workplace and in wider society. Organisations and people providing health and social care services must not discriminate unlawfully in providing their services on the grounds of several protected characteristics, including race. The Act also incorporates a general duty for public bodies to fully consider the impact that change in their policy will have on anyone with a protected characteristic.

Health and social care services covered by the laws under the Equality Act include (among others) all NHS providers and commissioners, those supporting elderly and disabled people in their homes, care in day centres, and residential or nursing homes.

Equality law affects everyone responsible for running an organisation or who might do something on its behalf, including staff or volunteers. The provisions of the Act apply regardless of whether services are provided for free or paid for by the service users or someone else.

Equality legislation in Northern Ireland is made up of several laws, the most significant of which in this context are the Northern Ireland Act and the Race Relations Order. Section 75 of the Northern Ireland Act 1998 places statutory duties on the public sector to have due regard for the need to promote equality of opportunity and the desirability of promoting good relations. The Race Relations (Northern Ireland) Order (the RRO), outlaws discrimination on the grounds of colour, race, nationality or ethnic or national origin. The RRO makes it unlawful to discriminate in the fields of employment, education, the disposal and management of premises, and the provision of goods, facilities and services.

NICE clinical guidelines state that health and social care staff should identify the specific needs of people with dementia and their carers arising from various characteristics, including ethnicity. Care plans should record and address these needs. Healthcare professionals should also be mindful of the need to secure equality of access to treatment for patients from different ethnic groups, in particular those from different cultural backgrounds. NICE clinical guidance applies in England and Wales but not Scotland. In Northern Ireland clinical guidelines are usually disseminated after general review.

Appendix 2: Case studies

A2.1 Bradford Metropolitan District Council information support and advocacy service

Service aimed at mainly Pakistani, Indian and Bangladeshi communities, but to a lesser extent also at established older Eastern European communities.

There was an acknowledged issue that many South Asian people with dementia and their carers in Bradford were not coming forward for information, support and advice services. The Meri Yaadain Dementia Team was established in response to this to offer a culturally competent service providing information, support, advocacy and practical help.

The Meri Yaadain service aims to accommodate cultural sensitivities around language, religion and customs, as well as the taboo around mental ill-health. The words Meri Yaadain mean 'my memories' across the six languages used by targeted South Asian communities. The service looks at the family circumstances of individuals and engages with them on a per-needs basis, for example accommodating that carers may not be next of kin or that next of kin may not be household decision-makers.

To raise awareness of the service, leaflets in the six languages commonly used in these communities were produced and disseminated. A website was also established with video and audio content. In addition, radio programmes, a community roadshow and a monthly support group were organised, alongside the production of a DVD designed to be viewed by a family seeking to better understand dementia.

The project has encountered challenges in terms of the taboo associated with tackling mental ill-health. Furthermore, the lack of a word for dementia in South Asian languages has meant it has been a struggle to get people to understand the condition.

The Meri Yaadain team has improved awareness of memory loss and dementia in the communities where it works and has expanded both its reach and also the size of the team itself. A 2008 review found positive outcomes and the team has won three national awards recognising its work.

In addition, the Meri Yaadain team has helped improve other service providers' awareness and understanding of cultural issues in the provision of information. It has also promoted greater involvement from people from the affected BAME communities in development of services and also in academic research, through participation with the evaluation of the programme.

For more information please contact Mr Akhlak Rauf, Project Manager, Meri Yaadain Dementia Team, akhlak.rauf@bradford.gov.uk, 01274 431308.

A2.2 Family carer using direct payments

C's mother is 86 years old and has Alzheimer's. She was diagnosed less than a year ago. It was very difficult for C's mother to get a formal diagnosis of dementia as the assessment at the memory clinic did not take account of the fact that C's mother is Chinese and so was not able to answer all the questions relating to English culture. C's mother lives alone in sheltered accommodation and C had concerns that her mother was confusing her medication. C's mother's native language is Cantonese and she is finding it harder to communicate in English as her condition progresses.

Keen that her mother should remain independent in her own home, C contacted the local authority to find some support for her mother. Although C found that there were services available for people with dementia in the local area, there was nothing which met the cultural needs of her mother. C decided that a direct payment could be a good option for her mother, thinking that she could employ a carer who spoke her mother's native language. Initially the local authority would not approve this service and C had to make a formal complaint in order to get the direct payment to employ a carer who could speak Cantonese. Using the direct payment, C now employs a Cantonese-speaking carer for her mother, but C has been training the carer in dementia care herself.

C felt that the local authority showed little cultural awareness, but also a lack of understanding of dementia. However, thanks to C's insistence, her mother now receives support suitable for her needs. This means that C's mother is now able to live independently in her own home and C is confident that her mother is taking her medication properly.

A2.3 Rochdale befriending service

Rochdale has a large South Asian population, as well as a substantial Polish community. In the past, Alzheimer's Society had set up a Dementia Café for people from BAME communities. However, this was not successful and found not to be culturally suitable for the people Alzheimer's Society was trying to help. This, in part, was due to the large stigma attached to dementia among South Asian communities which meant people with dementia were not comfortable going to a service with other people from their own or other communities.

Alzheimer's Society staff in the Rochdale area went back to the drawing board to rethink how to reach out to the South Asian families affected by dementia. With the help of funding from local health commissioners, Alzheimer's Society in Rochdale set

up a new befriending service in January 2013. This new service has a specific focus on befriending people from BAME communities.

The befriending service works collaboratively with several organisations, including the local memory service and South Asian community groups. The Befriending Manager attends events for the BAME community which helps to build relationships with the people from all communities. The Befriending Manager will now also start to recruit volunteer befrienders who can speak a range of languages and who have the cultural awareness to work with people from BAME communities. Referrals from the memory clinic to the befriending service are now starting to come through.

Alzheimer's Society recognises that this is a long-term project and will be monitoring the impact of the project and the challenges.

For more information please contact: Hayley Misell, Support Services Manager – Manchester, Oldham and Rochdale. Alzheimer's Society, Unit 15, Enterprise House, Manchester Science Park, Lloyd St N, Manchester, M15 6SE. Tel: 0161 342 0797. Email: hayley.misell@alzheimers.org.uk

A2.4 Royal Borough of Kingston upon Thames Admiral Nurse service

This Admiral Nurse service aims to meet the needs of a growing South Asian population in Kingston. While the majority of the population in Kingston is white British, there is a growing South Asian population composed primarily of Tamil-speaking Sri Lankans. Existing services for this community did not meet the needs of people living with dementia for a range of reasons including lack of understanding of dementia and stigma. As a result, people in this community living with dementia were often only accessing dementia services at a very late stage and only when support in their own homes had broken down.

An Admiral Nurse service, delivered by South West London and St George's NHS Trust and supported by Dementia UK, was put in place to raise dementia awareness in the community. The Admiral Nurse service aims to provide a service to all sections of the community and to ensure that language is not a barrier to access.

To inform the service and broaden its knowledge base, the Admiral Nurse conducted a literature review of the needs of this particularly community. To raise awareness of the service among the community and to build up trust and approval, the Admiral Nurse made contact with community leaders, including through face-to-face meetings.

The service also used suitably trained interpreters to meet information needs. Specific language barriers existed with there being no word for dementia in Tamil. Working with a Tamil-speaking old-age psychiatrist, a dementia awareness session was delivered to interpreters, with information about the session distributed widely in the borough.

A number of challenges were encountered in developing this service, including building up trust with community leaders and avoiding causing harm or offence to people in the community. Alongside these challenges, an additional barrier was the time pressure on people supporting the project, many of whom wanted to help but had little time.

Despite these challenges, the service has had significant success. The service has contributed to helping tackle stigma, raise awareness of dementia and promote early diagnosis and interventions. There has been a substantial increase in referrals to the Admiral Nurse service and the community team from the South Asian community. Feedback from participants in the awareness session was very positive. Staff at the South Asian community service, which had previously not been well suited to the needs of people with dementia, have now created a dementia resource pack and committed to improving their understanding and skills in supporting people with dementia.

Admiral Nurses are mental health nurses specialising in dementia and are supported by the national charity Dementia UK. For more information please visit www.dementiauk.org or call 020 7874 7203.

A2.5 Alzheimer's Society Connecting Communities Project

Having successfully secured three years' funding from the Department of Health for this innovative pilot, the Connecting Communities Project engages volunteers from BAME communities to design and deliver awareness-raising activities appropriate for diverse communities. The project will inform a BAME commissioning toolkit and volunteering best practice guidelines for the UK and London. This project will work to influence London-wide dementia service commissioning and set a standard for volunteering good practice. The project will focus on eight London boroughs with four full-time Volunteering Officers (VOs) working in two boroughs each. The eight boroughs are Croydon, Enfield, Hillingdon, Hounslow, Lambeth, Merton, Newham and Redbridge.

Many different communities are represented in London with different cultural perspectives on volunteering, dementia and local support services. Previous work to engage with communities has identified that it is important to consider communities individually. This project provides the opportunity to do just that, in order to address recognised issues around BAME groups' engagement with dementia care services, including:

- low awareness of dementia in BAME communities
- low numbers of people accessing preventative dementia services, instead engaging with support at a crisis point

- diversity of local volunteers not being reflective of demographic and target client base.

Early engagement work with London's diverse communities has confirmed a lack of awareness of dementia and local dementia services. At a recent awareness talk with a group of West African elders, one person gave the following feedback:

I want to take this opportunity on behalf of African Advocacy Forum to express our gratitude to your team for the great presentation. It was the first time we have ever discussed dementia at such a gathering and your presentation and the following discussions went a long way in creating a lot of awareness and answering some lingering questions about dementia.

The project works to develop culturally specific materials and approaches to ensure that knowledge about dementia is meaningful, appropriate and opens new discussions with diverse communities. Consultations will be held with community leaders, people with dementia, family carers and our volunteers on the best approaches to use and the terminologies which will best suit the different audiences. As the project progresses, the Connecting Communities Project will share its experiences and learning through three public events, through a commissioning toolkit and through a network it is establishing for people working in BAME areas.

For more information please contact: Alli Anthony, Connecting Communities Project Manager and Support Services Manager, Alzheimer's Society, Waltham Forest, 90 Crownfield Road, London E15 2BG. Tel: 020 8503 1613. Email: alli.anthony@alzheimers.org.uk

A2.6 Dementia awareness sessions and a community dementia LINK worker training programme for a range of BAME communities in Gloucestershire

A community-led programme in Gloucestershire has engaged the Asian, African and Chinese communities. It will soon be extended to Eastern European communities. Led by a community volunteer, this work has been organised through a number of 'community conversations'. Active listening highlighted that basic dementia awareness (around signs, symptoms, information and access to services) was needed.

A small group of people, including individuals closely linked to BAME communities and those from BAME communities, explored how best to deliver the awareness sessions. A half-day dementia awareness session was agreed, which included:

- 1 an informal and interactive conversation on dementia, including the signs and symptoms

- 2 how people from the communities viewed and experienced dementia
- 3 the information and services available for people with dementia
- 4 thoughts on how the dementia awareness session had been delivered.

The awareness-raising sessions were targeted at people from BAME communities who may have dementia, their carers and their families, or people from BAME communities who wanted information and knowledge on dementia. Recognising that different communities have both similar and different needs, each event was developed with input from the relevant BAME community to ensure it was appropriate. We also ensured the logistics and functional requirements met the specific needs of the community, for example a session for the Polish community took place on a Sunday afternoon, based on the community's feedback.

The benefits of the awareness-raising sessions include a much wider awareness of dementia, provision of the knowledge and information to openly challenge stigma and misinformation, and a sense of empowerment through shared learning and knowledge.

The BAME community dementia LINK worker course organically rose from, and worked in parallel with, the dementia awareness programme. This accredited course, of one day a month for nine months, includes modules looking at dementia as well as the support structures in place for people with dementia and their carers. The presentation material for the course was agreed through a working group that included individuals and carers from BAME communities, and organisations delivering dementia education and training. The course includes people from BAME communities giving an insight into their experience of caring for a family member with dementia. The course recognises that dementia needs for BAME communities are not homogeneous, and that participants, course tutors and speakers can all learn from one another.

Success has been measured at individual and community levels using quantitative and qualitative outcomes, including follow-up telephone calls and questionnaires. The knowledge gained from our work has been shared with BAME communities, taken back into the County Dementia Project Board and their respective agencies and organisations, and used to identify how to improve commissioning of services for diverse communities.

The programme started in January 2010 and is ongoing. Costs and resources are not just financial and the success of this ongoing work is based in successful relationships. It is felt that there is more to do to improve positive experiences of dementia services for BAME communities, but there has been a meaningful beginning.

I would like to acknowledge: Agnes Koszewska, Amina Kathdra, Chris Camm, Hein Le Reux, Helen Bown, Mary Keating, Saba Amjad, Sue Keane, Vera Li, and the many wonderful people and communities that have/continue to make this work happen.

For more information please contact: Bren McInerney, Community Volunteer, on 07940 045770 brenmcinerney@hotmail.com

A2.7 Somali Mental Health Network (SMHN) and Bangladeshi Mental Health Network (BMHN) in Camden

The Somali and Bangladeshi communities are the two largest BAME groups in Camden. The service was put in place because research showed there is a lack of awareness of dementia in the BAME communities in Camden, and that BAME communities are not accessing mainstream dementia services. Commissioned as Community Development Service (mental health) for the area, Voluntary Action Camden worked with the community to identify their needs and as a result established the mental health networks. These look at dementia along with other mental health concerns. Through the network, the communities share information and best practice and meet with providers to discuss issues. These discussions help to ensure services are tailored to meet the needs of the BAME community.

The service uses partnership working to promote its work. For example, Voluntary Action Camden has been working in partnership with the London Borough of Camden, NHS Camden, Tavistock and Portman NHS Foundation, Camden and Islington NHS Foundation Trust, schools, and a plethora of voluntary and community sector groups and organisations, including Somali and Bangladeshi agencies and older people's agencies. Using networks and working in partnership with the community and religious leaders, as well as dementia service providers and commissioners, the service is able to raise awareness of the service and engage the communities. The partnership working also improves the relationship with communities.

The benefits include increased awareness of dementia among the communities, thus destigmatising the issue. It also enables providers to meet with service users from the communities. Challenges have included engaging with certain community and religious leaders, particularly as some communities do not regard dementia as an issue for formal services. There is also a lack of knowledge among some staff working in the statutory sector regarding BAME issues.

Success was measured through feedback from the community groups, attendance at events and take-up of training.

Mr Somanah Achadoo, Voluntary Action Camden, tel 020 7284 6556, www.vac.org.uk

References

- Ablitt, A, Jones, GV and Muers, J (2009). Living with dementia: A systematic review of the influence of relationship factors. *Aging Ment Health* 13: 497–511.
- All-Party Parliamentary Group on Dementia (2012). *Unlocking diagnosis*. Alzheimer's Society, London.
- Alzheimer's Society (2012a). *Dementia 2012: A national challenge*. Alzheimer's Society, London.
- Alzheimer's Society (2012b). *Living with dementia*. March edition. Alzheimer's Society, London.
- Alzheimer's Society (2013a). *Diagnosis rate data*. alzheimers.org.uk/site/scripts/download_info.php?downloadID=1050 [Accessed May 2013].
- Butt, J. (2006). *Are we there yet? Identifying the characteristics of social care organisations that successfully promote diversity*. Social Care Institute for Excellence, London.
- Department of Health (2009). *The clinical and health economic care for early diagnosis and intervention services in dementia*. Department of Health, London.
- Department of Health (2012). *Prime Minister's challenge on dementia: Delivering major improvements in dementia care and research by 2015. A report on progress*. Department of Health, London.
- Knapp, M, Prince, M, Albanese, E et al (2007). *Dementia UK: The full report*. Alzheimer's Society, London.
- Lievesley (2010). *The future ageing of the ethnic minority population of England and Wales*. Runnymede and the Centre for Policy on Ageing, London.
- Moriarty, J, Sharif, N and Robinson, J. (2011). *Black and minority ethnic people with dementia and their access to support and services*. Research briefing. Social Care Institute for Excellence, London.
- National Audit Office (2007). *Improving services and support for people with dementia*. National Audit Office, London.
- National Audit Office (2010). *Improving dementia services in England – an interim report*. National Audit Office, London.
- Rauf, A. (2011). *Caring for dementia: exploring good practice on supporting South Asian carers through access to culturally competent service provision*. Meri Yaadain Dementia Team, Bradford.
- Social Services Inspectorate (1998). *They look after their own, don't they? Inspection of community care services for black and ethnic minority older people*. Social Services Inspectorate, London.