Same difference
Dementia in different communities

Black and minority ethnic communities project

Project Report
March 2003
The Alzheimer's Society is the leading care and research charity for people with Alzheimer's disease and other forms of dementia, their families and carers.

- Provides support for families through its network of branches, support groups and carers contacts
- Provides information and advice through its national help line, regional offices, branches and support groups
- Runs high quality day care and home care services which provide individualised support for the person with dementia and respite for their carer
- Funds research into the causes, possible treatments and care for Alzheimer's disease and other forms of dementia

Branches of the Alzheimer's Society

The Alzheimer's Society offers support through a network of 228 branches. Branches are formed by groups of members who wish to further the work of the Society in their local area. The branches are the local face of the Society and have a very important role in helping people with dementia and their carers on an on-going basis. Branches offer a range of services that include:-

- Emotional and social support, usually through a carers support group
- Information and advice
- Raising awareness about dementia and the need for services
- Befriending and carers support projects
- Day care and home care

What is Dementia?

Dementia is a term that describes a collection of symptoms which include memory loss and confusion. The conditions which cause dementia include Alzheimer's disease (which is the commonest), vascular dementia (which includes multi-infarct dementia), dementia with Lewy bodies, and Pick's disease. These conditions are terminal and there is currently no cure, although a number of drugs have been developed in recent years that seem to slow the development of the condition for some people.

In some cases memory loss and confusion can be caused by treatable conditions such as depression, thyroid problems, vitamin deficiency or even brain tumour. It is important to seek a diagnosis so that these conditions can be excluded.
<table>
<thead>
<tr>
<th>CONTENTS</th>
<th>page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acknowledgements</td>
<td>4</td>
</tr>
<tr>
<td>Introduction</td>
<td>5</td>
</tr>
<tr>
<td>Black and Minority Ethnic People and the Alzheimer’s Society</td>
<td>5</td>
</tr>
<tr>
<td>Background</td>
<td>6</td>
</tr>
<tr>
<td>Findings and Recommendations</td>
<td>7</td>
</tr>
<tr>
<td>Project Aims</td>
<td>9</td>
</tr>
<tr>
<td>- Raising Awareness</td>
<td></td>
</tr>
<tr>
<td>- Developing Partnerships</td>
<td></td>
</tr>
<tr>
<td>The Partners</td>
<td>11</td>
</tr>
<tr>
<td>- Friends of African Caribbean Carers and Suffers of Dementia</td>
<td></td>
</tr>
<tr>
<td>- Chinese Community Centre</td>
<td>12</td>
</tr>
<tr>
<td>- Amardeep</td>
<td>14</td>
</tr>
<tr>
<td>- Barnet African Caribbean Association</td>
<td>16</td>
</tr>
<tr>
<td>Project Training</td>
<td>19</td>
</tr>
<tr>
<td>The Project and the Alzheimer's Society Branches</td>
<td>21</td>
</tr>
<tr>
<td>Project Outcomes</td>
<td>22</td>
</tr>
<tr>
<td>Models of Good Practice</td>
<td>23</td>
</tr>
<tr>
<td>Contacts and Useful Addresses</td>
<td>25</td>
</tr>
</tbody>
</table>
ACKNOWLEDGEMENTS

The Society would like to thank all those people and organisations that have contributed to the Black and Minority Ethnic Communities Project. Many people gave their time and experience which has been invaluable.

We would also like to thank the members of the Project steering group and the project team for their guidance and support. We are grateful to the Department of Health and the City Parochial Foundation for funding the project and to the two project officers, Bolaji Bank-Anthony, who developed the project and Raksha Dattani, who wrote this report and to Jacky Mortimer, a consultant trainer, who provided the training.

Project Team
Jane Bell, Deputy Chief Executive
Janet Tyndale, Director of Branch Services
Peter Ackland, former Director of Branch Services
Joy Field, Head of Branch Services, South of England
Jacqui Wharrad, Regional Manager, London

Advisors: Susan Drayton, Brent Admiral Nurse Service, Danny Ho, Team Leader, CPN Elderly Team, Enfield

We are indebted to the four partner black and minority community groups who worked in partnership with us on this project.

BARNET AFRICAN CARIBBEAN ASSOCIATION
Maurice Archer, Development Officer, Seymour Jones, Treasurer, Paulette Slocombe, Chairman, Pam Jones and Stephanie Laldee, Care Workers

AMARDEEP, Mental Health Project for People of South Asian Descent
Anita Kalia, Manager, Dr K Gupta, Consultant and Committee Chairman, Mr M A Khan Lhodi, Outreach Worker

CHINESE COMMUNITY CENTRE
Richard Lam, Director, Sam Lui, Community Development Worker, Grace Lee, Camden Primary Care Trust

FRIENDS OF AFRICAN CARIBBEAN CARERS AND SUFFERERS OF DEMENTIA
Enid Jackson, Chairperson, Sidonie Hawthorne, Secretary
INTRODUCTION

The Alzheimer's Society believes that everyone who has dementia is a person with their own unique needs and aspirations. The Society aims to reach all people with dementia, their carers and families regardless of their background.

We want to challenge the assumptions people make about supporting people with dementia and their families from black and minority ethnic communities. The Society practices person centred care, this means recognising the whole person, including their cultural background and religion. The disease process is the same whatever our origin, how we perceive it will be affected by our culture.

The report is intended to give an overview of the work carried out by the project, the lessons learnt and some suggestions as to how other groups could use the recommendations within their own organisations. The resources section provides a reading list, useful tool kits, videos, website and contacts for those who want to explore further.

BLACK AND MINORITY ETHNIC COMMUNITIES AND THE ALZHEIMER'S SOCIETY

The Alzheimer's Society has a unique knowledge and understanding of dementia built up over the past 25 years from the experiences of people with dementia, their carers and the work of professionals in the field. However, it has limited experience of working with people in the different ethnic communities. In London we wanted to reflect the cultural diversity of the population and make our service accessible to the whole community.

The Black and Minority Ethnic Communities Project was set up to increase our understanding and to share our knowledge of dementia by working in partnership with people from the black and minority ethnic communities.

It is a pilot project designed to raise awareness of dementia amongst black and minority ethnic communities across London and to promote the provision of culturally appropriate social care services. We were fortunate in obtaining a three year grant from the Department of Health and the City Parochial Foundation to work in partnership with four community groups.

We have been able to combine the expertise and knowledge of the Society with the cultural understanding of these four partners and so reach out to people with dementia and their carers from African Caribbean, South Asian and Chinese communities.

The project employs an officer to work as part of the Society's regional team, and an advisory group comprising representatives from black and minority ethnic groups manages the project. The project started in November 2000 and ends with a national conference on 28 March 2003.
Project aims

- Help black and minority ethnic organisations recognise and understand dementia as a disease
- Provide them with the information and financial resources to develop their own expertise in dementia care
- Help them improve access to specialist services
- Learn how to make the Society at all levels more culturally sensitive with the help of partner organisations

The intended outcomes of the project are:-
- To strengthen the existing links between the Alzheimer's Society and various black and minority ethnic communities in London
- To increase awareness of dementia within these communities
- To have a fully trained team (including both staff and partner organisations) who can talk knowledgeably about dementia
- To establish culturally sensitive and accessible dementia care support services
- To disseminate information through three annual seminars
- Develop models of good practice

Background

The change in life expectancy in the population, leading to more people living longer, has also led to a growing number of black and minority ethnic people who are likely to develop dementia. The Alzheimer's Society found that these communities were not accessing their services and there was a significant amount of ignorance of dementia within the dominant black and minority ethnic groups. Developing this project would not only raise awareness of dementia amongst the chosen communities, resulting in a greater understanding and acceptance of the illness, but it would also inform the Society on the specific needs of the different communities.

The results of the 2001 census show that the minority ethnic population in England rose from 6% in 1991 to 9% in 2001. Black and Asian people comprised 60.6% of the population in the London borough of Newham and 54.7% in Brent. In 16 other London boroughs Black and Asian minorities accounted for a quarter or more of the population. 28.8% people in Greater London are from a black and minority ethnic community.

- 45% of Britain's black and minority ethnic communities live in London. 2.7 million Black and Minority Ethnic people live in Greater London
- There are still relatively few older people among these communities (56,000 people over 65) but this is set to change over the next fifteen years and so it is estimated that the numbers of people with dementia will rise accordingly
The Society’s branches in Birmingham, Sheffield, Newcastle, Leicestershire had each employed staff to work with black and minority ethnic communities. Bristol, Portsmouth, Bradford and Cardiff were making efforts to reach out to minority groups. In London the Society’s regional office jointly commissioned with Haringey social services an important piece of research which looked at the needs of three ethnic communities in the borough. These findings and the work of the branches provided the Alzheimer’s Society with important lessons about how best to work with different communities.

The Department of Health provided the Society with three year funding to develop this work in London. The experience of dementia among black and minority ethnic communities in London coupled with the support services that people from these communities need are areas where comparatively little was known. The Black and Minority Ethnic Communities Project was established in the autumn of 2000.

FINDINGS AND RECOMMENDATIONS

Raising Awareness

Videos

- These have proved a huge success in a variety of ways
- Now used Society wide for training purposes and awareness raising
- Proved useful in reaching communities other than those originally intended
- Needs to be available in other languages
- A great benefit was being able to provide them free of charge
- The length of time needed to produce them and get them right was greater than anticipated

Events/Conferences

- These were well attended with interest from within the Society as well as a number of other organisations interested in dementia
- They worked best when a joint venture between the partner and the Society
- Feedback was positive from participants
- Need to be on-going as people and circumstances change

Other literature

- Leaflet in 16 languages (Bengali, Chinese, Farsi, Greek, Gujarati, Hindi, Italian, Polish, Punjabi, Russian, Somali, Spanish, Turkish, Urdu, Vietnamese)
- Information pack for African Caribbean carers
- Information on dementia translated in Cantonese
Developing Partnerships

- The partners identified welcomed the opportunities provided by the project.
- It was hoped that five partners would participate but only four were identified. It took longer to establish relationships than anticipated so the decision was taken to concentrate efforts and resources on four partners.
- Appropriate training was key to the success.
- Assistance was required by the partners throughout to manage their project and to support their workers.
- In some cases the partners' resources were very limited therefore we needed to support them in practical ways. Providing the grant was not enough in itself.
- In conclusion one of the most effective ways of reaching black and minority ethnic communities is via existing relationships.
- The project has helped partner organisations recognise and understand dementia.

Training

- Training needs to be flexible in order to respond to the different participants.
- Needs to be in an easily accessible format and appropriate length.
- Evaluation and changes as appropriate are vital.
- Participants benefit from extra follow-up information/handouts that can be used in their work.
- Cultural awareness training was needed for members and staff of the Society to help inform them about working with people from different cultures.
- Black and minority ethnic trainers to be part of the training team.

Work with Alzheimer's Society branches and national organisation

- The project helped strengthen the existing links between the Alzheimer's Society and the various black and minority ethnic communities in London.
- The project enabled these communities to take an active role with the Society in Barnet and Lambeth.
- Many branches in London have changed the way they work with black and minority ethnic groups. They are more open and actively reaching out. The two videos have helped to bring this about.
- Enquiries from black and minority ethnic communities and related issues have increased since the start of the project.
- Branches throughout the Society are becoming more aware of the issues affecting black and minority ethnic communities and interested in working more actively with people from different cultures.
The Project Aims

**Aim: Help black and minority ethnic organisations recognise and understand dementia**

- Raising awareness

The project officer spent the first year networking with black and minority ethnic community groups and organisations. A database of contacts was developed and from these an advisory group of 37 black and minority ethnic older people’s organisations was established.

Culturally appropriate materials about Alzheimer’s disease and dementia were produced. This included leaflets in 16 languages, two videos, one aimed at African Caribbean communities and the other at South Asian communities.

These have been used to make presentations in London and in other parts of the country directed towards the black and minority ethnic communities to raise awareness and increase the understanding of dementia.

**Aim: Provide black and minority ethnic organisations with information and financial resources to develop their own expertise in dementia care**

The project set out to work with five partner organisations in selected areas of London. These partners would have few resources to carry out the work so the project set aside £75,000 to make partnerships grants available. In addition the Society provided travel expenses for volunteers as well as costs of providing alternative care if they themselves were carers.

- Developing Partnerships

Four organisations that were particularly interested in providing dementia services to their communities were chosen from the network of contacts. The groups lacked specific knowledge in Alzheimer’s disease and dementia and agreed to join the project in partnership with the Society.

Two partners supported people from African Caribbean communities, one in Barnet and the other in Brent. A third partner worked with people from the South Asian community in Lambeth and the fourth partner ran the Chinese Community Centre in central London.

Each of the four partner organisations demonstrated a different aspect of supporting people with dementia and their carers from black and minority ethnic communities.

- Developing appropriate literature
- Awareness raising activities and events
- Developing and enhancing appropriate services
- Training
- Support for local volunteers
1. Barnet African Caribbean Association
Provided a direct service to African Caribbean older people at a multi cultural centre. The partnership grant part funded the development worker, two care workers, reminiscence sessions and keep fit classes.

2. Amardeep
Provided awareness raising and outreach into the South Asian community. The partnership grant funded the work of the outreach worker for two days a week.

3. Chinese Community Centre
Provided awareness raising in the Chinese community through two conferences and the translation of information.

4. Friends of African Caribbean Carers and Sufferers of Dementia
Developed an information pack for the African Caribbean community produced in a culturally appropriate style and language.

**Aim: Help black and minority ethnic organisations improve access to specialist services**

Partner organisations were unaware of the services provided by the Alzheimer's Society and other specialist services before joining the project. Through workshops and information sessions they have been helped to recognise dementia and shown how to access specialist services.

**Aim: Learn to make the Society at all levels more culturally sensitive with the help of partner organisations**

From the information provided by the network of contacts, the partners and the organisations on the advisory group the project officer developed cultural awareness materials. These were used at workshops and seminars organised to inform the members, staff and volunteers of the Alzheimer's Society.

Using the example of the partnerships the Society’s branches were encouraged to create closer relations with their local black and minority ethnic communities as well as raising awareness of dementia.
The Project Partners

THE FRIENDS OF AFRICAN/ CARIBBEAN CARERS AND SUFFERERS OF DEMENTIA

The Friends of African/ Caribbean Carers and suffers of Dementia (FACCSD) promote awareness in all matters pertaining to dementia amongst the African/ Caribbean communities. FACCSD educate the community into the causes and symptoms of the disease and draw awareness to their cultural and religious needs.

Services

- Provide respite care to carers and suffers of dementia
- Outreach to day care centres, care homes and hospitals
- Deliver hair and skin care to African/Caribbean suffers of dementia in care homes and hospitals
- Liase and network with organisations for up to date information on all aspects of dementia and draw their attention to the cultural needs of the African/Caribbean carer and sufferer of dementia
- Awareness raising and information giving within the African/Caribbean and local community

The Partnership

The FACCSD were awarded a grant to formulate an information pack for African/Caribbean community carers of people with dementia and other voluntary and statutory organisations. The information included in the pack is as follows:

- What is dementia, causes and symptoms
- What help is available, useful tips
- Information for carers, looking after yourself, healthy eating
- Useful contacts

The information is presented in a culturally sensitive and acceptable format designed for the African Caribbean communities. The FACCSD has established expertise in dementia care and the information pack enables them to relay this expertise to the wider community. The grant has funded the production costs of 500 copies to promote awareness amongst the African/Caribbean communities throughout the country.

The partnership with FACCSD has helped the Alzheimer's Society develop an understanding of the African/Caribbean community and given FACCSD an opportunity to make information and services more widely available to carers of people with dementia from within their community.
CHINESE COMMUNITY CENTRE

The Chinese Community Centre aims to improve the quality of life and well being of the Chinese community, particularly those who are disadvantaged and work with them to meet their needs and be a focus in preserving Chinese culture, arts and identity.

Services

- Information and advice Bureau
- Immigration advice
- Elderly Project
- Youth Project
- Arts and music workshop
- Chinese Chefs School
- English Classes
- Health promotion for Older people

Chinese people, particularly the older generation, seem to experience difficulties and disadvantages due to language age and cultural barriers. This reduces their access to services. (Nearly 40% of the UK Chinese population live in London). It is important to overcome this gap in accessing services by raising awareness and promoting health issues that affect elderly people.

The Partnership

The Chinese Community Centre was awarded a grant to organise and deliver a programme of activities that included two one-day conferences, an information pack and publicity materials promoting knowledge, understanding and awareness of Alzheimer’s disease and other dementia’s targeted for the Chinese Community. The Chinese Community Centre worked hard and achieved the following:

- Familiarised themselves with Alzheimer’s disease and other dementia and its implication towards the Chinese Community
- Focused on the awareness and understanding of dementia and identified the high-risk groups
- Developed a programme of activities in conjunction with the target groups in the Chinese Community
- Liaised and networked with statutory health authorities and voluntary bodies
- Translated information on dementia into Chinese and developed an information pack for the Chinese Community to promote awareness using leaflets based on the translated version from Dementia in Hong Kong
Organised two one-day awareness events in January 2003. The first conference was aimed at professional workers and 70 people attended. The topics included Alzheimer’s disease, causes and cures, social care for people with dementia and a Chinese perspective on dementia. The second conference was for Chinese elders and 100 older people attended. An interpreter translated the presentations into Cantonese.

Staff from the Chinese Community Centre attended training provided by the Alzheimer’s Society to gain further knowledge of Alzheimer’s disease and dementia. This gave them a greater understanding of the disease and helped to disseminate information and raise awareness amongst the Chinese community. The consultant trainer commissioned by the Alzheimer’s Society to carry out the training on behalf of the Black and Minority Ethnic Communities Project also helped the Chinese Community Centre plan the two conferences.

"Endless time has been spent on the specific problem of how to translate the word dementia into Cantonese. Much amusement has been furnished by the current Cantonese language leaflet from the Alzheimer’s Society which seems to say something about Sex in the characters it uses to describe dementia. It is interesting to find that the nearest characters that translate, either talk about mental illness, (a negative concept), or older people (a positive one, but which excludes younger people with a dementia). The stigma that mental illness confers on those with mental health problems is very much current in this, as well as in many other Black and Minority Ethnic communities."

Jacky Mortimer
Consultant Trainer
AMARDEEP

Amardeep (mental health project for people of South Asian descent) is part of the South London and Maudsley Mental Health Trust. It provides a specialist multi-agency mental health service that is culturally acceptable and responsive to people from South Asian descent living in Lambeth who have serious and persistent mental health difficulties. The service is targeted at people who are unable to, or are refusing to, use mainstream mental health services because of language, cultural or racial factors.

Services

- Raise awareness of mental health issues in the south Asian community
- Develop meaningful links with appropriate agencies and professionals in statutory and voluntary sectors, community groups, service users and families
- Case management and outreach support
- Drop in and group work support
- Specialist advice and information

The Partnership

Amardeep was awarded a two year grant to raise awareness of dementia within the Bangladeshi, Indian & Pakistani communities in Lambeth and to identify carers, families and people with dementia from these communities. They have recruited an outreach worker who comes from within one of these communities. He works two days a week visiting South Asian community groups in the borough, as well as religious establishments such as temples. The worker has made contact with health and social services, older people and other community groups in Lambeth and neighbouring boroughs.

The outreach worker has raised awareness about Alzheimer’s disease and dementia within the South Asian communities by preparing and disseminating information and giving talks on ‘What is dementia?’ Through this networking he has already identified 150 carers’ families and 24 people with dementia.

With the help of Amardeep and the Black and Minority Ethnic Communities Project he organised an Alzheimer’s and dementia awareness event that took place in October 2002. The awareness day was a forum to bring together the community, religious groups and individuals that had contact with the outreach worker. It brought about greater awareness of Alzheimer’s disease and dementia within the South Asian community. 100 people attended.

The Black and Minority Ethnic Communities Project provided training and support for the outreach worker. The funding from the Society ceases in 2003. Towards the end the outreach work will be reduced and Amardeep and the outreach worker will be looking at developing appropriate forms of support networks for people with dementia and their families. The Society will work with Amardeep to try and secure further funding to continue and build on the success of this project.
The project involved fieldwork, visits during unsociable hours, training sessions, meetings/seminars and awareness raising events. The Amadeep project has exposed a lack of knowledge generally amongst the South Asian community in Lambeth. The outreach worker has managed to introduce and raise some awareness of Alzheimer’s disease and dementia in the south of the borough. However there is a substantial Bangladeshi community in the north of the borough still to be reached.

The outreach worker was asked to visit a client with dementia, who was having trouble expressing himself verbally. He had already been visited twice by the Social Worker who did not speak his Asian language and the man’s wife had never learnt English. The outreach worker described how he had gone up to the man and made the traditional male greeting in their culture - the client embraced him and was able, with tears, to begin to describe, with some language, what was happening to him. The Social Worker commented he had been able to collect fifty times the amount of information in that Assessment visit, than on the two previous visits. This underlines the importance, not just of an interpreter, but also of someone who can understand the experience of that person with dementia (the isolation, the loss of self-esteem, the inability to verbalise easily and the crucial need for physical reassurance and support).

As told by Mr M A Khan Lhodi
Outreach worker

The partnership between Amardeep and the Alzheimer's Society has led to the development of a relationship with the local Lambeth branch. The outreach worker became a member of the branch management committee. This relationship will continue to the benefit of both organisations.

“Since linking with this project I have a fair understanding of what Alzheimer’s and dementia is about. This has been gained from some basic reading, training and visiting centres that have members with dementia related illnesses.

The training received through the project and the Society has been very good. However, dementia is a very wide field, it would be advantageous for more training to be available with physical and practical exposures for hands on job experience. This would serve to enrich the quality of future care provision.”

Mr M A Khan Lhodi
Outreach worker
BARNET AFRICAN CARIBBEAN ASSOCIATION (BACA)

Barnet African Caribbean Association (BACA) provides activities & support for older African Caribbean people within the borough of Barnet. They provide a forum where older people from African and Caribbean communities can meet to socialise and support each other.

Services

- Provide a forum at the Barnet Multi/Cultural Centre where older people from African and Caribbean communities can meet to socialise and support each other
- Run a stroke club two days a week
- Provide freshly cooked cultural hot meals
- Run keep fit class, arts and crafts, reminiscence, sewing group
- Provide outreach work in the borough
- Provide information and advice on health, education, employment, housing and benefits

The Partnership

BACA was awarded a two year grant to fund the development worker one day a week and a care worker two days a week, to provide culturally appropriate support to the six people with dementia that attend the stroke club. In addition to this the project aimed to provide support to carers of people with dementia, develop appropriate reminiscence and training material, become more informed and aware of Alzheimer's disease and dementia and raise awareness in the Barnet area.

There is still a stigma attached to mental health problems and Alzheimer's disease and dementia amongst black and ethnic minority communities. BACA with the help of the Alzheimer's Society has attempted to overcome this stigma by hosting a number of awareness days. These events have clarified some of the myths associated with the disease, however it has been difficult to target large groups and raise awareness throughout the whole community.

The development worker promotes the centre by networking with other organisations such as residential homes, doctor's surgeries and local support groups. BACA advertises its services via leaflets, however the African Caribbean communities in Barnet are scattered and it is difficult to know which areas to specifically target.

The day centre runs two days a week on Tuesdays and Fridays and they currently have eight members with dementia. Four people with Alzheimer's disease or dementia have been recruited since the partnership was formed. Unfortunately, due to limited resources such as a lack of carers for specialist needs, they have had to turn away three potential members. Even with the support of the Alzheimer's Society project, it has been difficult to meet the growing needs of this community in the borough.
The development worker works full time and spends two days a week with the members and the remainder of the week forming links with other organisations to promote the centre. With funding from the partnership BACA was able to employ additional staff to help run the day care service. This allowed African Caribbean people with dementia to continue to attend and benefit from being with people who share their cultural background. Training and support for the centre workers was provided by the Alzheimer's Society. It is now important to expand and continue to support this development.

Quote from development officer

“Having members in their own cultural environment plays a very important part in their development, giving them the confidence to talk about the past because they can see that the group have experience and understand about what they are saying. Most of the clients when they are communicating with each other refer to the past by saying “do you remember when at home (in Africa or the Caribbean) we used to do this” they then start listening to what he or she has to say. When we are playing cultural music some of them get up and start dancing. Going back to their cultural experiences creates fun, joy and laughter.”

Mr Maurice Archer
Development worker

Quotes from the members of the centre:

“I go to another centre on Wednesday but I prefer this one, you can talk and I also like the food”

“When I am here it is like home from home”

“Since I started coming to the centre I am feeling a lot better I am with my friends”

One of the aims of the partnership was for BACA to develop a working relationship with the Barnet branch of the Alzheimer’s Society. This has been achieved and the strengthened relationship has led to some joint undertakings.
BACA Awareness Raising Event

In July 2002 during Alzheimer’s Awareness Week BACA co-organised an event, with the Barnet branch, which also involved Barnet Asian Elders Association and Barnet Primary Care Trust. The aim was to raise awareness of dementia within black and minority ethnic communities in the borough.

The programme included a talk on the causes of dementia by one of the local consultants in old age psychiatry, information about the Society and other sources of support, information and services locally. A Black carer whose mother has Alzheimer’s disease talked about his personal experiences. The local M.P was unable to attend but sent a letter that was read out about his family experiences of dementia and the Society's video,' remember me' was shown. The Primary Care Trust provided an interpreting service for the event, which was also attended by the Council Leader and Deputy Mayor.

This brought together over one hundred people from black and minority ethnic backgrounds and was so popular that they have decided to continue to work together on raising awareness. In 2003 they hope to put on an event aimed at community leaders and others workers within black and minority ethnic communities.
The Project Training

To ensure that the training provided was culturally sensitive the project team engaged a consultant trainer who was knowledgeable and experienced in providing training on dementia and working with people from other cultures. The project funded four training sessions.

The following workshops were designed for staff and volunteers from the partner organisations:

1. Working with people from different cultures
2. Communicating with people with dementia
3. Working with carers

The fourth workshop was open to branch staff and volunteers only:
4. Working with people with dementia from different cultures

Training Plan

Although a training plan was written at the start, it was changed in order to respond to the needs that emerged. This meant that the topic for the next training workshop was identified at the end of each of the training days.

Points to remember:

- The training must be flexible in order to respond to what the participants bring to the workshops
- The training needs to be delivered in an easily accessible format
- Extra follow up information must be made available to the delegates such as resource information and additional research references
- The workshops need to be kept to a suitable length by taking into consideration time restraints for staff and volunteers

Where needed, follow up information was sent after the workshop, for example information from Age Exchange on the use of reminiscence materials for Afro-Caribbean people. Afro-Caribbean projects are often unaware that mainstream organisations have developed materials to meet their specific needs. It was also useful to include information on how some kinds of dementia may be more prevalent because of other health conditions.

One focus of the training was to assist the workshop participants in recognising dementia in people they already knew. After only two workshops they were able to recognise the signs of dementia and had gained basic knowledge about the different types of dementia giving them increased confidence to ask questions.

Part of the training was organised to help the participants reach out to others in their community. This was why the third workshop was about Carers and their needs. During this workshop it was strongly evident that each of the partners had understood the importance of supporting carers and were thinking of ways they could respond.
Outcomes from the training were:

- Awareness of the barriers faced by black and minority ethnic communities when accessing services and ways of identifying any gaps
- Solidarity amongst black and minority ethnic communities
- Improved awareness of each other’s cultures
- Black and minority ethnic organisations changing their service to respond to the needs of people with dementia
- Use of appropriate training materials that black and minority ethnic groups could relate to
- Opportunities for networking
- Sharing of good practice between branches of the Alzheimer’s Society

As a result of the training some individuals significantly improved their ability to respond to people with dementia and gained new skills in leadership and advocacy in their communities.

**Evaluating the training**

A variety of methods were used:

- Training sheets evaluating each day
- The collection of anecdotal material
- The observation of changes in individuals practice and the new initiatives undertaken by those people

**Quotes from the evaluation sheets**

“The trainer was very positive and encouraging to all “

“I need more information about communication with people with dementia- how to approach them”

“I would have liked more information about encouraging integrated services, instead of culturally sensitive services that are segregated- we need ways of improving our recruitment drives to Black and Ethnic Minority staff”

One commented “today has only scratched the surface - would be good to have more to build on this”.

Handouts “Excellent and straight to the point”
The Project and the Alzheimer's Society Branches

This pilot project has given branches in London an opportunity to work more closely with groups representing black and minority ethnic communities.

South West London Branch

The outreach worker in the borough of Wandsworth attended the training and awareness events organised by the project. She used the information she gained to help her make really good links with Asian and African Caribbean services in her area and is able to offer practical help and support, rather than just speaking about dementia.

She now has a plan to do some joint training on dementia in the borough, linking voluntary organisations such as Age Concern, Crossroads and the black minority ethnic community groups.

Barnet Branch

How the project has had an impact on the way the branch works.

"The branch’s specialist day centre for people with dementia is working more closely with both BACA day centre and the Asian Elders day centre to try and ensure that people with dementia benefit from all our areas of expertise whichever centre they attend. We can help with information about dementia and any difficulties that may arise and they can help us with information about people’s cultural needs and how we can best work with them. This new closer working has enabled us to share information and hopefully have made BACA and other organisations feel more comfortable about contacting the branch.

The branch decided that their AGM this year should be a celebration of the diversity of cultures within the community in Barnet through the medium of food and music. Food was shared from the Caribbean, South Asian, and the Jewish culture. Lunch was followed by music and performers from the African Cultural Association, dancers and musicians from the Asian day centre, and ended with traditional Irish music. It was good to see how the Indian musicians listening to the Irish music obviously recognised some familiar themes and how the audience joined in with both the Indian dancers and danced to the Irish tunes.

Knowing and understanding each other’s background and culture’s is an important first step in breaking down barriers. The initiative from the Society, making available money and other resources to groups like BACA to enable them to have control over the resources to provide services to people with dementia within their community. This followed up with support and information will also break down barriers and encourage people from black and minority ethnic communities to see the Society in a more positive light.”

Jo Cahill
Branch Manager
The Project Outcomes

The existing partnerships between the Society and black and minority ethnic communities will become stronger and we will begin to develop new relationships. We would like to see more involvement of these communities in the Society.

- The existing relationship between the Barnet African Caribbean Association and the Barnet Branch has been strengthened as a result of the partnership and joint working will continue after the project has ceased
- A new relationship has developed between Amardeep and the Lambeth Branch. The branch committee is considering ways to continue the partnership and to develop joint initiatives with the Amardeep outreach worker
- The information pack developed by the Friends of African Caribbean Carers and Sufferers of Dementia could be used as a model for other groups to follow
- The new relationship established with the Chinese Community Centre has been a rewarding experience. The Community Centre staff have been eager to learn and understand how to support Chinese elders with dementia. We hope to build on this relationship and plan further joint awareness events

Increased awareness of dementia within these communities

- The outreach work undertaken by the Amardeep project amongst the South Asian community in Lambeth has begun to raise awareness of dementia. This was aided by the simple explanation of the disease given by the presenters at the Alzheimer's Awareness Day in October. Those attending were older people from the local South Asian community who were helped to recognise and understand dementia as a disease
- The two conferences organised by the Chinese Community Centre were designed to increase awareness amongst the Chinese community. Before the partnership was put in place the Chinese Community Centre had no understanding of dementia

A fully trained team (including both staff and partner organisations) who can speak knowledgeably about dementia

- The training courses provided for the partners helped the staff and volunteers to pass on to members of their community what they had learnt about dementia and providing support to carers

The establishment of dementia care support services that are accessible to the communities they serve

- The services to older people with dementia provided at the multicultural centre in Barnet have been developed using the expertise gained from this project. Before the partnership was set up the Barnet African Caribbean Association was unable to offer a dementia care support service
Cultural awareness workshops were provided to educate members of the Society to be more culturally sensitive and adopt a more person centred approach when dealing with people from different cultures. The workshops took place at regional meetings in the London, Eastern and Southern regions and at the Society’s AGM in September 2001 and 2002.

Two annual seminars concluding in a national conference

The videos ‘remember me’ and Sahara Lo were each launched at a seminar, one in London and the other in Birmingham. In March 2003 the project concludes with the first national seminar to be held by the Alzheimer's Society on working with people from black and minority ethnic communities.

The development of models of good practice

During the course of the project the Society has produced some models of good practice that have emerged from the work. These have been produced in leaflet form, on tapes and were presented in workshops and reports and have been translated into a number of appropriate languages.

- Leaflets
- Tapes
- Videos
- Language line

Often in black and minority ethnic communities using literature to disseminate a message is not the most effective means of communicating, especially if the literature is not culturally appropriate.

Videos

To help make dementia more easily understood two videos were produced, one for the African Caribbean communities and the other for South Asian communities. The videos also helped people understand that the disease does not discriminate and can affect anyone despite race, religion or ethnic origin.

The video’s featured people from the communities themselves who had Alzheimer’s disease or another form of dementia showing that anyone could develop the disease.

The videos proved to be very effective communication tools and were responded to better than other means of raising awareness. The response to the videos has been so overwhelming that they are now being used for training purposes both within the Society and externally.

'remember me'

A video to introduce dementia and caring within African Caribbean communities, presented by Paul Barber, featuring Lydia who is 90 years old. Lydia has been visiting a day centre for there years. While she is there she has a nice time, meets other people, chats with friends and sings. When she gets home, her daughter asks her if she has had a good time at the club. Lydia replies, 'What club? She doesn't remember where she has been.
'Sahara Lo'
A video to promote understanding of dementia in South Asian communities, introduced by Saeed Jaffery.

"Some families from the Asian communities don't like to seek help. They prefer to keep it hush hush" (Alzheimer's Society outreach worker)

"My mother was a clinical psychologist for 30 years. Because she has a work history of treating people with Alzheimer's disease and dementia, she finds it difficult to accept the same could happen to her". (Son of Asian lady attending a day centre)

Website

The project has a web page on the Society's website, which provides information on the aims, objectives and developments of the project (www.alzheimers.org.uk/ethnic-minorities). This site had 3,719 visitors in 2002.

Good Practice Guide: a tool kit for working with cultural diversity
Jacky Mortimer, Training Consultant

The Good Practice Guide is the result of the work carried out with the Alzheimer's Society as part of the Black and Minority Ethnic Communities Project. The guide is divided into two sections. Section one sets out the key lessons identified and section two offers the materials to carry out the training. Copies of the guide can be obtained from the Alzheimer's Society, London Regional Office.

Project Report

A full report of the project including a report on the national conference 'Same difference - Dementia in different communities' will be published later in the year. Copies will be sent to the people who attended the conference and those who participated in the project. Details of how to obtain a copy will be found on the website.
Contacts and useful addresses

Alzheimer's Society
Gordon House
10 Greencoat Place
London SW1P 1PH

Tel: 020 7306 0606
Fax: 020 7306 0808
Helpline: 0845 300 0336
Email: info@alzheimers.org.uk
Website: www.alzheimers.org.uk

Alzheimer's Society
London Regional Office
45-46 Lower Marsh
London SE1 7RG

Tel: 020 7620 3020
Fax: 020 7401 7352
Email: rol@alzheimers.org.uk

Amardeep
380 Streatham High Road
London SW16 6HB

Tel: 07958 134643
020 7919 3400

Barnet African Caribbean Association
Barnet Multicultural Community Centre
Algernon Road
London NW4 3TA

Tel/fax: 020 8202 0095

Chinese Community Centre
2nd Floor
28/29 Gerrard Street
London W1D 6JP

Tel: 020 7439 3822
Fax: 020 7734 3572
Friends of African/Caribbean Carers and Suffers of Dementia
Unit 47A Park Royal Business Centre
9-17 Park Royal Road
London NW10 7LO

Tel: 020 8965 1112
Email: friends@dementia.fsbusiness.co.uk

JMBM Training
5 Clifford House
Edith Villas
London W14 8UG

Tel: 020 7610 4490
Email: jmbmtraining@clara.co.uk

Brent Admiral Nurse Service
Central & NW London Mental Health Trust
Belvedere House
341 Harlesden Road
London NW10 3RY

Tel: 020 8830 4459

Department of Health
Wellington House
133-155 Waterloo Road
London SE1 8UG

Tel: 020 7972 2000

City Parochial Foundation
6 Middle Street
London EC1A 7PH

Tel: 020 7606 6145

Commission for Racial Equality
St Dunstan’s House
201-211 Borough High Street
London SE1 1GZ

Tel: 020 7939 0000

The Alzheimer’s Society is the leading care and research charity for people with all forms of dementia, their families and carers. Founded in 1979 as the Alzheimer’s Disease Society. Patron: HRH Princess Alexandra, The Hon Lady Ogilvy, GCVO. President: Dr Jonathon Miller CBE. Chairman: Dr Nicholas Carey. Vice Chairman: Irene Kerr. Hon Treasurer: Anita Monteith FCA ATII. Chief Executive: Harry Cayton OBE. Alzheimer’s Society, Gordon House, 10 Greencoat Place, London, SW1P 1PH. Tel: 020 7306 0606. Fax 020 7306 0808. Website www.alzheimers.org.uk Email info@alzheimers.org.uk Registered Charity No 296645. Company Limited by Guarantee. Registered in England No 2115499