Bringing Dementia Out of the Shadows for BME Elders

A Report on the Work of the Ethnic Minorities Dementia Advocacy Project (Emdap)

To March 2009
Executive summary of the Ethnic Minority Dementia Advocacy Project 2009

The project
This report is on work undertaken with the aid of a Department of Health grant made to Westminster Advocacy Service for Senior Residents (WASSR) and the Dementia Advocacy Network (DAN) to
- raise awareness of dementia and dementia advocacy amongst Black and Minority Ethnic (BME) communities and to support these communities in providing dementia advocacy services for their members;
- raise awareness amongst existing advocacy services of the need to make their services accessible to older people from BME communities and with dementia,
- and to support these advocacy providers by sharing expertise and providing training;

This national project was based in a small local advocacy organisation, WASSR, as a result of the charity’s work over many years developing dementia advocacy and undertaking outreach to local Black and Minority Ethnic Communities.

The project is timely because of the publication of the National Dementia Strategy early in 2009, the government’s drive towards personalization of services that requires that people who have difficulty in accessing services for whatever reason will need skilled advocacy to enable them to voice their needs and the wish to address health inequalities.

Resources attached to the Project
EMDAP was funded by the Department of Health to provide a project worker and organisational support for 3 days a week. Supervision and co-ordination was provided by the Manager of the Dementia Advocacy Network. During the later phases of the project funding was found from within the WASSR budget to increase the project worker’s hours to 4.5 days a week.

Important findings of the research
- Very little is known of the numbers or of the experience of BME people with dementia. A reasonable estimate is that in 2007 there were between 10,000 and 10,500 people over 65 from BME groups, with dementia and resident in England.
- That many BME community organisations know little of the prevalence of dementia in their communities, the nature of dementia and are unaware of the services available, including dementia advocacy.
- That for some BME communities there are additional cultural barriers to the diagnosis and access to support to BME people with dementia. There is prejudice, shame and fear attached to dementia for many and a tradition of keeping it within the family.
- That many advocacy organisations lack the knowledge understanding and skills to outreach to people with dementia in the BME community.
  - That few advocacy organisations have the resources to support people with dementia in the indigenous population, let alone BME people with dementia.

The project has succeeded in
- mapping the low level knowledge about the BME population with dementia numbers and their experience of dementia and the existing (minimal) provision of dementia advocacy for BME elders.
- raising awareness of the need for and value of dementia advocacy with two kinds of organisation, advocacy providers and BME community groups through workshops, training sessions, conference presentations and through advocacy network events and publications.
- developing awareness raising and training materials and approaches that have been very positively received
• developing good practice guidance for advocacy organisations wishing to outreach to BME people with dementia.
• Identifying gaps in provision and offering suggestions for projects to take the work forward

Working with advocacy providers
Extensive feedback from training sessions and workshops conducted by the project shows great appreciation of the high level of understanding of diverse cultures and the need for a sensitive approach to less familiar cultures that is felt to be fundamental to success in working with BME communities. The frustration for providers is the lack of resources means that they find it difficult to extend their work into areas that need investment over time building relationships and understanding since these do not produce quick results that funders want.

“There are so many barriers - language, non verbal communication, history, cultural background, protocols. In some groups there is a stigma attached to dementia. BME people with dementia don’t get listened to and don’t understand.” An advocacy worker

Working with BME community organisations
The research indicates that the groups that have been supported by the EMDAP have gained valuable information about dementia and advocacy and that BME group workers have been able to use the skills and knowledge gained to help identify relevant problems and to signpost to available services.

But the evidence gathered as part of this evaluation indicates that the process of finding BME support groups, getting to know them, working with them and successfully encouraging community led advocacy projects is likely to take much longer than initially expected. This aspiration is also hampered by the lack of funds and other resources available to BME support groups, making any new project difficult to establish.

“We need to get into the BME communities, raise awareness of dementia and show it isn’t a problem families have to struggle to deal with alone. This is a long slow process, often leading to high frustration on both sides. Often a lot of discussion takes place, but it doesn’t seem to move forward and become action. We need to understand cultural differences and how these relate to expressing wishes and needs effectively.” A BME community group worker.
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Introduction and acknowledgments

This report is into the work of a national project based in a small local charity working to support older people, looking at the provision of independent advocacy for older people with dementia who are from Black and Minority Ethnic Communities (BME). This is a group of people who experience double or even treble discrimination — as older people, as people with dementia and as people from BME communities. They are perhaps more in need of access to independent advocacy than any other group.

Yet the Ethnic Minorities and Dementia Advocacy Project (EMDAP) Report provides some startling insights not only into the lack of provision of dementia advocacy in general but to the virtually complete lack of advocacy provision for this group. Beyond that it seems to reveal a huge gap in knowledge of the prevalence and needs of BME elders experiencing dementia amongst statutory services, a range of professionals AND among BME community organisations. Ignorance and cultural barriers seem to have combined to hide this issue from view. Almost in an aside the report reveals that there are very few BME elders in residential care, but there appears to be no understanding of why and how this has happened.

The Report therefore offers a very important contribution not just to advocacy but also to the implementation of the National Dementia Strategy with its commitment to equality of service. It is for this reason that perhaps the most important part of the Report is Section 4 in which the team at DAN and WASSR has identified a number of projects to focus on the priority areas for future work. We urge funders, both statutory and charitable, to support these projects and others which will address the needs of this most vulnerable section of the community.

That this issue has been addressed at all is due to a number of people and organisations:

Firstly and most importantly the Director and Board of Trustees of Westminster Advocacy Service for Senior Residents (WASSR). This local advocacy service dedicated to supporting older people was quick to identify that if it was to work with all the local community it must support people with dementia. WASSR's pioneering work in this field has led to the development of very considerable expertise and its acknowledged role in offering training nationally. This in turn led to the invitation from the Department of Health to co-ordinate and lead the Dementia Advocacy Network to help disseminate good practice nationally.

In particular the work of WASSR's Director Irene Kohler, who master minded this initiative, Sally Wells who pioneered the dementia advocacy at WASSR and Jan Kendall, the present Manager of the DAN, who steered the EMDAP Project must be acknowledged.

We are also grateful to the funders of the Project, the Department of Health and the funders of the DAN, initially the Baring Foundation and the Department of Health again and now the Tudor Trust.

Gona Saed, the Project worker who conducted the work on which the report is based has contributed tremendously to our understanding of the present state of dementia advocacy for BME Elders, to the development of good practice.

And lastly, we thank WASSR's researcher Jill Jones for all her work in collating the information and bringing the issues to light in this evaluation report.

Jill herself wants to acknowledge the work of those who supported her in conducting the evaluation. She says:

"During the course of this evaluation I spoke to many people working in advocacy, working with BME communities and in relevant support organisations. Everyone I spoke to was helpful, open and seemed genuinely pleased to be asked for feedback. Thank you all for your co-operation.

Thanks also to the DAN Steering Committee for your early input to the evaluation.

Without the input of the staff of the EMDAP, the DAN and WASSR this evaluation would not have been
possible. Thank you for your patience and tenacity and for finding the time to deal with the many emails and queries I have thrown at you”  Jill Jones May 2009
Section 1  Background to the EMDAP Project

1. National context for the project
   - Historically, dementia has attracted the dual stigmas of mental illness and old age, resulting in poor public understanding of the disease and cause for concerns over the lack of professional understanding and provision of appropriate services.

   - Over the last ten years, largely as a result of pressure exerted on government by voluntary sector support groups, the will to address the needs of people with dementia and their carers has moved up the political agenda. Early in 2009 the government published a National Dementia Strategy, with the key objectives of: increasing public and professional awareness of dementia; promoting early diagnosis and intervention; radically improving the quality of dementia care; taking steps to improve research into the causes of and treatment for dementia. Early diagnosis is known to be cost effective: appropriate treatment can postpone high dependence on carers and improve the quality of life for people with dementia and their carers.

   - The National Dementia Strategy promises better services for people with dementia, dementia related training for GPs and other health workers, specialist dementia workers and memory clinics plus a campaign to raise public awareness of dementia. The framework for the delivery of the Strategy includes the need to address health inequalities relating to dementia.

   - In tandem with putting pressure on government, voluntary sector support groups have also successfully campaigned to raise public awareness. As a result issues relating to living with dementia are now more commonly discussed or depicted in the media. Support groups and the NHS have produced relevant printed, web-based and telephone information and the media provide links so the public can access this information. Much of this information is translated into a range of languages.

   - In addition to the issues around dementia, there are known to be additional barriers experienced by BME groups when accessing services. As a result they are more likely than their white compatriots to delay seeking help. Language difficulties and cultural misunderstanding also lead to an increased risk of delayed diagnosis or misdiagnosis. Mental health issues for people from BME groups are particularly likely to go unnoticed by medical practitioners.

   - Two thirds of people with dementia in the UK live in the community and are cared for by informal carers as well as through statutory care in the community. 62% of people living in care homes have some form of dementia, although only 28% of care home places are registered to provide specialist dementia care. Older people from BME communities appear to be significantly under-represented amongst care home residents.

   - It is the Government’s intention to make all services “user centred” and to adopt a case management approach to the provision of health and social care. There is a stated intention to involve voluntary organisations and to ensure access to advocacy for those who need help when expressing their wishes in relation to the provision of these services. Recently developed national qualifications in independent advocacy and quality performance schemes for advocacy services will help voluntary organisations prepare for this challenge.

2. Advocacy and dementia
   - Expectations that advocacy will be available to help those who need support in accessing services have been raised, particularly as a result of the introduction of the Mental Capacity Act and the National Dementia Strategy. The Mental Capacity Act makes provision for Independent Mental Capacity Advocates (IMCAs) and more recently statutory advocacy has been extended through Independent Mental Health Advocates (IMHAs). Of the 39 organisations listed in the Older People’s Advocacy Alliance (OPAAP) report of 2006, only two said they had specific dementia advocacy projects.

   - Historically there have been very few advocacy services for people with dementia. WASSR has
played an innovative role in this field, starting in 1997 when WASSR first obtained funding to pilot a Dementia Advocacy Project. The project has continued, providing a vital advocacy service to older people with dementia in Westminster and a valuable source of expertise, information and training for service providers and others throughout the London area and beyond. During the life of the project WASSR staff have built up experience in and knowledge of advocating for people with dementia. They have been instrumental in developing tools and shaping good practice for the delivery of dementia advocacy at the local and national level. Emerging from this basis of expertise WASSR has taken on the role of facilitating and managing the National Dementia Advocacy Network (DAN).

3. Dementia in BME elders
- In 2007 the Alzheimer's Society estimated there were 700,000 people with dementia in the UK, of whom an estimated 1.6% (11,200) were from BME groups. BME groups have a higher incidence of early onset dementia. England has a higher proportion of people from BME communities than other parts of the UK.

Taking these two facts into account, a reasonable estimate is that in 2007 there were between 10,000 and 10,500 people over 65 from BME groups, with dementia and resident in England.

- The population of England is ageing and predictions for 30 years time are that 25% will be over 60 and 10% over 75. Whilst non-white groups have a younger age profile than average, the number of older people in BME groups will increase, reflecting past large-scale immigration patterns.

- At the same time that advocacy is moving up the national agenda, there is increased focus within advocacy on addressing the needs of BME communities. As a result of equalities legislation and influences such as the advocacy Quality Performance Mark Scheme for organisations providing Independent advocacy, the Standard Support Project and the new National Advocacy Qualification (NVQ) level 3 Certificate in Independent Advocacy, advocacy providers must now be proactive in addressing BME issues. The National Dementia Strategy also contains the intention to address health inequalities relating to dementia. All this has reinforced the need to build expertise, share this expertise and provide information and training relevant to providing advocacy for people from BME communities who have dementia.

4. Local context for the EMDAP project
- Westminster Advocacy Service for Senior Residents (WASSR) provides trained advocates to enable all older people in Westminster to express choice about matters affecting their everyday lives and so improve their quality of life. In addition WASSR works to inform older people and service providers locally and nationally about the benefits of advocacy for older people. This work includes: the development and provision of training in advocacy and working with older people; active involvement in local and national networks; contributions to national conferences.

- WASSR has also played an innovative role in developing advocacy for people with dementia identifying this as essential to a comprehensive service to older people from its earliest days. It is known as a centre of excellence in this work.

- The City of Westminster is home to a wide range of black and minority ethnic (BME) communities, accounting for over 30% of the population and speaking over 100 different first languages. Over the next ten years Westminster is expected to become even more ethnically diverse and the age structure of groups will change, with the average age of many groups increasing. Within the BME community in Westminster, African-Caribbean is the largest group, although, compared with the rest of London, there are large Chinese and Bangladeshi groups.

- Early in the new century WASSR came to realize that the ethnic profile of its clients did not match the ethnic profile of the older residents of Westminster, with clients from minority ethnic communities being significantly underrepresented. In 2002 WASSR first began outreach work to BME communities in Westminster and by 2007 the number of referrals from these communities had increased to over 50% of all clients. It was a logical development of this work to provide
dementia advocacy to elders from these communities, so in 2006 further funding enabled WASSR to outreach to BME clients with dementia.

- In 2003 WASSR was awarded funding by the Baring Foundation to pilot a national network for those working in the field of dementia advocacy. The network grew from an informal group of people who had been sharing experiences and common problems, to become the Dementia Advocacy Network (DAN), funded from 2004 by the Department of Health (DH) and currently funded by the Tudor Trust. In 2006 the DAN was awarded further DH funding to begin development work with people with dementia and from BME communities. This became the Ethnic Minority Dementia Advocacy Project (EMDAP).

5. The EMDAP project described
The Ethnic Minority Dementia Advocacy Project (EMDAP) is a national project with three strands:

- to raise awareness of dementia and dementia advocacy amongst BME communities and to support these communities in providing dementia advocacy services for their members;
- to raise awareness amongst existing advocacy services of the need to make their services accessible to older people from BME communities and with dementia, and to support these advocacy providers by sharing expertise and providing training;
- to share expertise on advocating for people with dementia and from BME communities nationally.

During the period under review the EMDAP has undertaken proactive outreach work to BME groups nationwide, provided a range of learning material, training and experiences to help people in these groups understand dementia and the importance of dementia advocacy. Locally this work has resulted in increased referrals to the dementia advocacy service from the minority ethnic communities of Westminster.

The EMDAP has worked with members of the DAN and other advocacy providers to encourage extension of their work to be inclusive of and accessible to BME communities. WASSR has developed and continues to develop training for people working in dementia advocacy. The EMDAP has contributed through training in outreach to and advocating for BME communities. This training is available to individuals and groups interested in the field of dementia advocacy with BME communities.

At a national level the project has engaged in active networking, helped to stage and contributed to conferences and produced learning materials both for dementia advocacy and for professionals working with BME groups. It also serves as a source of information and support to groups applying for funding and wanting practical advice when trying to establish advocacy projects for BME groups.
Section 2 Evaluation of the EMDAP project

1. Methodology
The evaluation of the Ethnic Minority Dementia Advocacy Project (EMDAP) has been undertaken in two stages. The first stage took place at the end of 2007 as the EMDAP developed. This stage was designed to assess the then current need for and provision of advocacy for people with dementia and from Black and Minority Ethnic (BME) Communities. The second stage of the evaluation was undertaken at the end of 2008 into the beginning of 2009. This stage had the dual objectives of identifying the impact of the EMDAP on the provision of advocacy for people with dementia and from BME communities and identifying gaps in provision with ideas about how these might be filled.

Both stages have involved:
- interviews with people who have used the services of the EMDAP, including advocacy workers,
- people working with BME groups, people working in advocacy and BME networks;
- email questionnaires to relevant support groups and service providers;
- review of material published on the web and in print;
- discussion with the EMDAP Steering Group and WASSR, DAN and EMDAP workers;
- review of quarterly progress reports to the funders and internal information.

The list of appendices to the report included in the table of contents will give readers an idea of the scope of the evaluation.

2. Anticipated outcomes from EMDAP

The application for funding submitted to the Department of Health outlined the achievements and new benefits expected as a result of the project. These were:

a) Advocacy schemes for older people with dementia will be more aware of ways of working with BME groups. This will enhance access to independent advocacy for BME elders with dementia.

b) There will be increased and shared knowledge of dementia amongst BME groups. This will help to dispel myths and overcome any unhelpful attitudes towards dementia by people from BME cultures.

c) Specific training on dementia advocacy for BME communities and their advocates, will be developed to help increase access to advocacy for elders with dementia in these communities.

d) BME issues will be included in the training for specialist statutory advocates.

e) Sharing of knowledge of cultures and attitudes towards dementia will help make advocacy schemes across the country better equipped to work with BME groups.

f) Inclusion of older people with dementia and from BME communities in the planning of advocacy services.

g) Building on WASSR’s work with volunteers to provide the advocacy service and its outreach work to BME groups will help groups develop their own volunteering and advocacy service for their elders.

h) An increase in the number of referrals to WASSR’s dementia advocacy service from BME communities in Westminster.

i) Increased awareness of diversity amongst staff of advocacy services leading to more creative and positive approaches to making advocacy services in general more accessible to BME older people.

j) Identification and development of opportunities for partnership working amongst DAN members and other advocacy providers to work with BME communities.

The expected beneficiaries of the project were:
- BME elders with dementia;
- advocacy schemes seeking to make their advocacy service accessible to BME elders;
- BME groups wishing to support their elders in gaining access to services;
- BME workers (including volunteers) gaining advocacy skills which will enhance their career development;
- service providers, by gaining better understanding of the needs of BME communities and how to be accepted by those communities.

3. Resources attached to the project

The EMDAP was funded by the Department of Health (DH) to provide a project worker with organisational support for 3 days a week. Supervision and co-ordination was provided by the Manager of the Dementia Advocacy Network, originally funded by the Baring foundation and the DH for 3 days a week but since January 2008 a full-time post funded by the Tudor Trust. During the later phases of the project funding was found from within the WASSR budget to increase the project worker's hours to 4.5 days a week.

4. The Baseline

The research project benefited from a mapping exercise and report compiled by the Older Peoples Advocacy Alliance (OPAAL) in July 2006 that established a baseline for the work of the project. This identified the following characteristics of the provision of Advocacy for older people, older people with dementia and BME older people found at the start of the EMDAP project:

- Patchy provision: provision of advocacy for older people was patchy and development of this service nationally was not systematic. OPAAL also found that the notion of advocacy was almost unknown to older people and awareness amongst organisations working with older people was limited at the policy level, advocacy for older people had a very low profile in spite of the benefits it can bring.
- Services being cut: At the time of the OPAAL survey many organisations providing an advocacy service for older people were being required to cut back or even cease operations because of the lack of funding.
- Lack of dedicated dementia advocacy: of the 39 organisations listed in the OPAAL report, only two said they had specific dementia advocacy projects. WASSR was one of a very small number of organisations during the 1990s to recognise the need for access to advocacy for older people with dementia. A mapping exercise in 2003 conducted by Dementia North identified 35 organisations providing dementia advocacy as a stand alone service or by using specialist dementia advocates in the context of a broader advocacy service.

At the same time other evidence suggested that:

- Expectations were being raised, particularly as a result of the introduction of the Mental Capacity Act and its provision for Independent Mental Capacity Advocates (IMCAs).
- There was a lack of focus within advocacy on BME communities: a few DAN members represented projects working specifically with BME communities – WASSR and Alzheimer’s Concern Ealing in particular. WASSR’s own outreach work to local BME communities had resulted in an increase from below 25% to over 50% of all clients to its dementia advocacy work coming from these communities.
- The personalized services agenda at the same time the government was stressing its intention to make the provision of services “user centred.” This case management approach to the provision of health and care services highlights the need for many more trained advocates to help ensure access to advocacy for all clients.

All indications are that there is a significant need and a nationwide gap in the provision of advocacy services for older people with dementia and from BME groups.

Published research to support this hypothesis is scarce. However the research document on BME health
advocacy published by the King’s Fund in 2005 identified a nationwide lack of advocacy services for older people with dementia and from these communities.

Another useful source was a report produced by the Joseph Rowntree Foundation in 2002 describing the results of research into the needs for advocacy services of BME mental health service users in the Trent and Yorkshire areas of the NHS. This research found that
- Where services existed they were inaccessible and often inappropriate to the specific needs of BME users;
- BME users felt that mainstream Mental Health service providers misrepresent, misunderstand and seek to control BME users’ experiences and methods of expression;
- BME led projects were significantly less well developed than mainstream projects;
- Interpretation is necessary, particularly for South Asian groups;
- Many potential users did not understand the concept of advocacy and this led to low uptake of advocacy services;
- Service users were isolated in the community and did not know that advocacy exists;
- Whilst mainstream advocacy providers suggested they were developing posts to improve advocacy for BME groups, none were actually fully engaging with BME groups;
- BME service users felt most empowered when they had an advocate reflecting their culture, gender and ethnicity.
- The research also found that the experiences of BME advocates operating within what they perceived as a hostile environment left them exhausted and frustrated.

It was against this background that the DAN decided to develop the EMDAP to help achieve equal access to dementia advocacy for BME communities.
Section 3 Key findings

1. Measurement against expected outcomes

An assessment of the work of the EMDAP project against the outcomes identified at the start of the project is given below. Direct feedback from organisations benefiting from the work of the EMDAP is contained in Appendix A5.

a) Advocacy schemes for older people with dementia will be more aware of ways of working with BME groups. This will enhance access to independent advocacy for BME elders with dementia.

- Through its work with the DAN the EMDAP has made members of the network aware of ways of working with BME groups.
- There have been 80 attendances at DAN meetings with workshops on working with BME groups.
- Information has been sent to all 171 DAN members and general presentations made at a number of DAN meetings.
- Dementia awareness training has been undertaken with Health workers, BME workers, advocates and associated volunteers. Over 200 people have taken part in 15 training events.
- One to one contact has been made with over 20 advocacy organisations, resulting in the delivery of BME dementia advocacy workshops and training sessions with associated literature and ongoing support.

b) Increased and shared knowledge of dementia amongst BME groups. This will help to dispel myths and overcome any unhelpful attitudes towards dementia by people from BME cultures.

- DAN information is distributed on a regular basis to 40 BME groups.
- Workshops, talks and awareness raising sessions have been undertaken with 13 BME groups reaching over 380 BME older people and workers.
- Information has been distributed to, and further work planned with a further 10 BME groups. Feedback from group organisers is very positive; an increased understanding of dementia and its implications is reported by participants (recorded in Appendix A5).
- Sessions delivered in the group's own language were found to be especially helpful.

c) Development of specific training on dementia advocacy for BME communities and their advocates, to help increase access to advocacy for elders with dementia in these communities.

- Specific training in, or direct help with dementia awareness and advocacy for BME communities and their advocates has been developed and delivered by EMDAP.
- Material has been prepared in a number of languages and learning experiences developed appropriate to a number of different cultures.

d) Inclusion of BME issues in the training for specialist statutory advocates.

- The EMDAP project has been instrumental in providing expertise to help ensure BME issues are included in the training for specialist IMCAs and IMHAS.
- Input has been made to the programme leading to the National Advocacy Qualification NVQ Level 3 module on Understanding and responding to the needs of different advocacy groups.
- The EMDAP contributed to the Quality Performance Marks scheme for organisations providing independent advocacy and the associated guide (On Your Marks) developed by Action for Advocacy and aimed at those starting a new advocacy scheme.

e) Sharing of knowledge of cultures and attitudes towards dementia to help make advocacy schemes across the country better equipped to work with BME groups.

- The EMDAP has worked with 16 advocacy or BME projects outside Greater London and with 10 national networks or support groups. Outreach through the DAN has enabled the EMDAP to share knowledge of cultures and attitudes towards dementia to help make advocacy schemes across the country better equipped to work with BME groups.
- Networking with BME groups across England, attending conferences, being part of working groups and talking to national umbrella groups for older people and BME communities has laid the foundation for an increased understanding by BME project workers of dementia and how it is viewed within a wider range of cultures.
- In the early stages of the project half-day training sessions in dementia advocacy for BME communities were
provided by EMDAP. As a result of input from trainees and the enhanced experience of the project worker, training is now extended to a full day and includes a case study, a number of exercises, the social and legislative context and information about services for people with dementia.

f) Inclusion of older people with dementia and from BME communities in the planning of their advocacy services.

To date there are few advocacy services specifically for older people with dementia and from BME communities. Where these are being planned there is no evidence people with dementia are being involved. However there is evidence that BME groups are being involved or at least consulted. Advocacy project workers who have attended EMDAP led training and workshops have found the sessions on how to outreach to BME communities particularly useful when planning consultation with the BME communities.

g) Building on WASSR’s work with volunteers to provide the advocacy service and its outreach work to BME groups will help groups develop their own volunteering and advocacy service for their elders.

- The EMDAP’s outreach work to BME groups has not directly resulted in the development of community led volunteering and advocacy services for their elders.
- Feedback indicates that groups are gaining valuable information about dementia and advocacy and BME group workers are able to use skills and knowledge gained to help identify relevant problems and to signpost group members to available services.
- However the evidence gathered as part of this evaluation indicates that the process of finding BME support groups, getting to know them, working with them and successfully encouraging community led advocacy projects is likely to take much longer than initially expected. This aspiration is also hampered by the lack of funds and other resources available to BME support groups, making any new project difficult to establish.

h) An increase in the number of referrals to WASSR’s dementia advocacy service from BME communities in Westminster.

There has been a significant increase in the number of referrals to WASSR’s dementia advocacy service from BME communities in Westminster. During the time there was no outreach worker in post referrals dropped off, demonstrating that outreach needs not merely to be initiated but to be maintained.

i) Increased awareness of diversity amongst staff of advocacy services leading to more creative and positive approaches to making advocacy services in general more accessible to BME older people.

It is clear from the information gathered through interviewing advocacy workers who have attended EMDAP training and workshops (included as Appendix A6) that they have gained increased awareness of diversity. Most are positive about the need to find ways to make their services accessible to BME communities in their area of operation. However for many limited funding means that they will have to find ways to do this within their current work. Few will have the resources to develop pro-active and innovative approaches.

j) Identification and development of opportunities for partnership working amongst DAN members and other advocacy providers to work with BME communities.

The EMDAP has developed partnership working with a number of advocacy organisations and with some umbrella groups. The DAN meetings and other events give members the opportunity to network and to develop partnership working. The proposed projects in Section 4 of this report identify a range of potential partners for future work.

Extensive feedback from training sessions and workshops show great appreciation of the high level of understanding by the EMDAP project worker of diverse cultures and the need for a sensitive approach to less familiar cultures.

2. WASSR’s expertise before, and acquired in the course of the project

- Before this project commenced, WASSR had extensive expertise in advocacy, dementia advocacy and BME outreach work. It also had considerable experience of delivering training in advocacy and in developing volunteers.
- During the course of the project, WASSR’s expertise in BME outreach and dementia advocacy has been combined to develop a programme of work through which the EMDAP helps other organisations to understand dementia and how to outreach to BME communities. Training courses,
awareness raising sessions, workshops, publications and training material have been developed. The skills to find and approach potentially interested organisations and to deliver learning experiences have all been enhanced during the course of the project. The project worker has learnt to adopt a flexible approach, tailoring delivery to a range of people such as professional health care workers, advocacy workers, BME group organisers and older people from BME communities.

- The EMDAP project worker has developed the skills needed to participate in and make presentations at national conferences; give input to national training and accreditation programmes; to take part in consultations at a national level.

- Outreach to local BME communities in Westminster has resulted in an increase in the number of clients with dementia from these communities. This in itself has improved the outreach and dementia advocacy skills of project workers and added to the overall knowledge base of the EMDAP, the DAN and of WASSR.

3. How expertise has been shared and developed over the course of the project

- The EMDAP is a part of the DAN and has shared expertise with dementia advocacy projects through DAN publications, meetings, training sessions and workshops. The project worker has also established contact with a wide range of BME groups and delivered information sessions to a number of these projects. To March 2009 the EMDAP has worked with a total of 26 BME groups or advocacy providers from the greater London area and 16 from provincial towns or cities. Group training or awareness raising has been undertaken with 19 of these Greater London based groups and 11 from provincial towns or cities.

- At a national level expertise has been shared at national conferences, through publications and articles in appropriate literature and by working with national umbrella groups and networks. The project worker has undertaken work with 10 national groups or networks and made presentations or conducted workshops in conjunction with seven of these.

- Expertise in working with BME groups is being shared with other members of the WASSR team. Local outreach before and during the project has resulted in an increase in the proportion of clients from BME groups using the dementia advocacy service from 25% to 50%. The ways in which EMDAP shares its expertise are listed below: quantitative and qualitative information to illustrate the extent and influence of shared expertise can be found in the appendices.

  - Dementia awareness training
  - Workshops on BME and dementia
  - Workshops and training on outreach to BME communities
  - Interactive presentations and information sessions
  - Attending meetings and conferences
  - Publishing material including material in languages other than English
  - Giving help and advice ranging from information to consultancy - telephone, email, face to face, either at WASSR offices or on the other party's premises
  - Encouraging BME groups to join the DAN
  - Input to national training programmes
  - Input to national advocacy provider quality mark scheme
  - Input to consultation documents

4. Links with other dementia and advocacy support organisations

The EMDAP has worked with a number of other support organisations to develop the provision of advocacy for older people from BME communities. Examples are:

- Contributing to Action4Advocacy's Quality Performance Marks scheme and associated On Your Marks publication.
- Workshops and "knowledge cafes" at a recent Age Concern England (ACE) conference
and also at the National Advocacy Network Conference.

- **EMDAP is a member of Age Concern England's BME Elders Forum.**
- **The project worker contributed to the Older People's Advocacy Alliance (OPAAL) conference May 2009.**
- **On a more local level, training for advocates and BME workers has been organised in collaboration with Age Concern Camden and Alzheimer's Concern Ealing, adding to their own measure of success in this area of work.**

5. Gaps in advocacy and related provision for BME older people with dementia

The research for this evaluation has identified significant gaps in the provision of advocacy for people from BME communities and gaps in associated support for this advocacy. These are outlined in Appendix A6. Gaps are reported in

- the actual provision of advocacy,
- appropriate training for advocacy providers,
- awareness raising activities
- appropriate Information and resources
- and in the co-ordination of services.

Provision of advocacy: there are few advocacy projects working pro-actively to provide advocacy for people with dementia in specific minority ethnic communities. Specific projects for people with dementia from BME groups are rare (Alzheimer's Concern Ealing is one example) although a few advocacy providers are in the planning stage with BME projects or work with local health and social care providers to improve BME referral rates to dementia advocacy projects.

Other groups said they did not discriminate, but find it difficult to find resources to actively target people from BME communities and/or people with dementia. Many of these groups would like to do more to improve their ability to work with BME people with dementia. If advocates do not have a thorough understanding of the language and culture of that community, advocacy is not accessible to the older members. Whilst generic advocacy providers will provide advocacy for anyone within their target age group and geographic area, very few have the funds or the skills to effectively reach local minority ethnic groups.

Appropriate training for advocacy providers: the EMDAP has been active with these groups, providing training, advice and learning resources and is becoming known as a significant source of expertise and help. But there is a need for comprehensive and ongoing training for advocates working with people with dementia and from BME groups. Advocating for people from BME communities does not appear to be included in the diversity training of all advocacy providers. This training needs to cover the broader aspects of working with BME communities, such as: how to make contact and work with the specific minority ethnic communities likely to be encountered; how to recruit volunteers from these specific communities; how to work with interpreters; how to involve the families of people with dementia. Training is also needed for BME and other community group workers in advocacy skills, ageing and dementia awareness, supporting people with dementia and the services available.

Health and social care professionals need training in working with people with dementia and from BME groups. Service providers are not always aware of the needs of the BME groups they work with and the fact that advocacy is available. The national strategy to encourage early diagnosis of dementia must address the special needs of people from BME communities.

Awareness raising is needed at the national level to continue to educate the public about living with dementia.

Special effort is needed to reach BME communities, to help community members understand dementia and the services available. The approach to this awareness raising needs to be designed in the light of each community's historic attitude to dementia. Information about dementia, services available and how to use the services needs to be fully accessible to community members. Those working in BME communities need to be aware of the value of advocacy for people with dementia.
Appropriate information: relevant training and educational material is needed in a wide range of languages. There is a need to develop more ways to pool and share information between advocacy providers.

And co-ordination: advocacy is an important tool to help older people with dementia remain in control of their lives. An important contributor to this is effective sharing and co-ordination between statutory agencies, voluntary and community groups. It is evident from the experience of some advocates that this does not always happen.
6. General conclusions

1. Research for this evaluation has focused on a limited number of advocacy schemes and BME community groups. It is clear that during the first two years of the project the awareness of the need for dementia advocacy for people from BME communities has been raised - but from a base of virtually nil awareness. Much of this awareness raising is due to the work of the EMDAP and the way in which experience and knowledge is shared through the work of the DAN. The knock on effect of the introduction of the Mental Capacity Act and the provision of IMCAAs has also helped to raise awareness of the need for advocacy for people with dementia and the need to be able to advocate for hard to reach groups such as BME communities.

2. There seems to be an acute lack of quantitative and qualitative data about the health and social care needs of the BME community. This means little is known about their needs and how these are best met. It also means there are few examples of how to get the information needed to plan for and obtain funding for local or national BME advocacy projects.

3. Specifically, there would seem to be an acute shortage of hard data in advocacy about the BME population. Few advocacy groups interviewed in the course of research for this report had numerical information about the local BME population. None had information about health amongst the elders in that population and it seems there is no substantive national information about the number of BME elders with dementia. Those working with care home residents commented that few older people from BME groups were represented and that no one seems sure why this is the case. Changes are needed. Many of these are outlined in the National Dementia Strategy. Others are described in the DH's document Delivering Race Equality in Mental Health, although it is not clear how this will affect older people with dementia.

4. The forthcoming Equality Bill is being introduced to promote fairness and equality; tackle disadvantage and discrimination; modernise or strengthen the law to make it fit for the challenges that society faces. Public bodies will be required to consider the diverse needs and requirements of both their workforce and the communities they serve.

5. Effective advocacy for BME older people with dementia is essential to ensure they are able to access existing and planned services, they have an equal opportunity to remain in control of their own lives for as long as possible and to ensure the National Dementia Strategy and associated plans become a reality for their communities.

6. One of the biggest challenges society will face is that of supporting the growing number of people with dementia. Dementia advocacy should be an important tool to help in this, and is likely to be particularly needed in the support of BME communities.

7. Work is needed to change the attitudes of funders so they are more willing to recognise the need for sustained funding to help provide advocacy for people with dementia and from BME communities.
Section 4 Taking the work forward: some project proposals

The work of the EMDAP Project is important and ground breaking. It has identified a group of people for whom support is badly needed, exposed gaps in our knowledge as well as our provision.

The team at WASSR and the Dementia Advocacy Network has identified a series of project proposals to provide ways in which the preliminary work undertaken in the EMDAP project can be carried forward. The proposals are indicative of the areas of concern: the list is not definitive and WASSR is anxious to discuss these and other ideas with potential partners and/or funders in both the statutory and voluntary sectors.

WASSR and DAN are very happy to work with potential partners or funders in any way that will move towards greater access to dementia advocacy and allow progression towards equality in dementia services.

<table>
<thead>
<tr>
<th>Project 1 Dementia and Advocacy Awareness for Local Minority Ethnic Communities.</th>
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<tbody>
<tr>
<td><strong>Project description</strong></td>
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</table>
| **Project aims**                                             | • To raise awareness of memory loss and dementia in those identified communities,  
                                                                   • To gain an understanding of the particular language and cultural differences that can cause barriers to accessing services,  
                                                                   • To explore ways of providing dementia services appropriate to the specific communities  
                                                                   • To then enable the advocacy services to offer a service which is appropriate and easily accessible.  
                                                                   The project meets at least two of the main objectives (1 & 4) of the National Dementia strategy: to improve public awareness and understanding of dementia and address the stigma of mental health and enable easy access to care and support |
| **Potential partners**                                       | Link with a research project on dementia in bme communities e.g via Kings Fund, Joseph Rowntree Foundation, Beth Johnson Foundation, Alzheimer's Society or Local Alzheimer's Society branches. |
| **Outcomes**                                                 | • Increased awareness and understanding of dementia as experienced in specific communities,  
                                                                   • Understanding of the cultural barriers to accessing services within specific communities  
                                                                   • Provision of appropriate information on dementia services to hard to reach communities  
                                                                   • Enabling a specified number of people from bme communities to access information and services with the support of an independent advocate.  
                                                                   • Developing further guidance on good practice |
### Project 2  Action Research into Effective Outreach to BME communities.

| Project description | • This project will seek to document evidence of effective outreach to specific BME communities from a range of disciplines including advocacy, consultation, and elder abuse.  
• The research will aim to identify common barriers, and consider different methods of engagement and identify successful models. The project will be pro-active in seeking feedback from the presentations, training and seminars which form part of the action research.  
• This evidence will be used to enable advocacy schemes to learn effective methods of engaging with BME communities to increase referrals for advocacy from these groups.  

*This project meets the objectives of the Equality Act 2006 on equal access to services and protecting from discrimination.* |
| Project aims | • To develop successful models of community outreach to specific communities  
• To increase access to dementia advocacy for people from BME communities |
| Potential partners | • Action for Advocacy  
• Action on Elder Abuse  
• BME Elders Forum (Age Concern and Help the Aged)  
• Equalities and Human Rights Commission  
• National Dementia Strategy Implementation Team |
| Outcomes | • The production of guidelines for effective outreach to specific BME communities with clear examples of good practice and successful models.  
• Identification of legislation that impacts on minority ethnic communities. |

### Project 3  Training for BME Workers in Dementia Awareness and Accessing Services

| Project description | • This project will provide and promote training for workers in various BME communities.  
• The topics covered will include coping with memory loss as one gets older, identifying signs of dementia, awareness of services available to support individuals and families  
• The project would use the established model of facilitating BME workers to develop skills to enable them to support those in their communities to find their way through the health and social services pathways and thereby access appropriate support.  

*This project meets Objectives of the National Dementia Strategy (1,3,4,14) on improving public awareness and understanding of dementia, providing good quality information, enabling access to support and advice, and providing an informed and effective workforce for people with dementia.* |
| Project aims | • Increasing access to services for BME elders with dementia  
• Providing good quality information to BME elders  
• Increasing the skills of BME workers |
| Potential partners | • Alzheimer’s Society  
• Age Concern BME Forum  
• Social Services Departments/commissioners of services |
| Outcomes | • Increased awareness and understanding of dementia within the 'hard to reach' BME communities.  
• Earlier referrals for diagnosis of dementia.  
• Easier access to support through facilitation of informed advocates within the communities.  
• An informed and effective workforce amongst BME communities. |
## Project 4  Training for health and social care professionals

### Project description
- This project will provide training for health and social care professionals in understanding the best way to engage with people from minority ethnic backgrounds who have dementia and their families.
- The training would provide information on the different perceptions of mental health especially memory loss and dementia in various communities, along with other barriers which hinder communication and uptake of services.
- The project will assess the value of independent BME specialist advocates to support individuals from these communities.

*This project meets the objectives of the National Dementia Strategy (1,13) which aims to improve professional awareness of dementia and provide an informed and effective workforce for people with dementia.*

### Potential partners
- Health and social services departments and commissioners of services
- BME Community organisations

### Project aims
- Enhanced skills in the workforce
- Increased professional awareness of dementia
- Increased access to services for BME elders

### Outcomes
- Health and social service professionals will gain necessary skills to provide the best quality of care in the roles and settings where they work for people from minority ethnic communities.
- Awareness and understanding of dementia and how it impacts on specific groups of people will be improved and thereby social exclusion and discrimination reduced in those communities.

## Project 5  Care Home Advocacy

### Project description
- This project will promote group and individual advocacy in local residential care homes.
- It is a response to the unmet needs of the increasing numbers of people with dementia in care homes, many without families to advocate for them.
- The project will provide hard evidence of the numbers of BME elders with dementia in residential care homes in relation to the local population profile and their unique needs.
- The project will assess the effectiveness of the advocacy intervention.

*Meeting Objective 11 of the National Dementia Strategy on living well with dementia in care homes and potentially informing those seeking to meet objectives 14 and 16 – a joint commissioning strategy and a clear picture of research evidence and needs.*

### Potential partners
- Local advocacy schemes
- Joint commissioners of services
- Local BME communities
- Care home providers

### Outcomes
- Increased awareness and understanding of the unique needs of BME elders with dementia amongst managers and care workers in care homes.
- Support for vulnerable adults in care homes to ensure their human rights are acknowledged and defended.
- Support for BME residents of care homes to ensure their wishes and preferences are listened to and met on an equal basis with other residents.
Sources of information

Organisations

Action for Advocacy
Advocacy Resource Exchange
Advocacy Training
Afya Trust
Age Concern
Alzheimer's Society
Audit Commission
Better Government for Older People
Care Services Improvement Partnership (CSIP)**
National Coalition of Citizen Advocacy Schemes
CSIP Black and Minority Ethnic Mental Health**
City of Westminster
Committee of Public Accounts
Dementia Advocacy Network (DAN)
Dementia Care Trust
Dementia North*
Dept. for Communities and Local Government
Department of Health
Equality and Human Rights Commission
Friends of the Elderly
Healthcare Commission
Joseph Rowntree Foundation
Medical Research Council
Mental Health Foundation
MIND
National Audit Office
National BME Mental Health Network
NHS Choices
NHS Information Centre
National Institute for Clinical Excellence (NICE)
Office for National Statistics
Office of Health Economics
Older People's Advocacy Alliance (OPAAL)
Policy research Institute on Ageing and Ethnicity
Social Care Institute for Excellence
The Guardian
The Kings Fund
Westminster BME Health Forum

www.actionforadvocacy.org.uk
www.advocacyresource.org.uk
www.advocacytraining.org.uk
www.afyatrust.org.uk
www.ageconcern.org.uk
www.alzheimers.org.uk
www.audit-commission.gov.uk
www.bgop.org.uk
www.olderpeoplesmentalhealth.csip.org.uk
www.cacoalition.org.uk
www.nimhe.csip.org.uk
www.westminster.gov.uk/communityandliving
www.publications.parliament.uk/pa
www.wasr.org/dementia
www.dct.org.uk
www.communities.gov.uk
www.dh.gov.uk
www.equalityhumanrights.com
www.fote.or.uk
www.healthcarecommission.org.uk
www.jrf.org.uk
www.mrc.ac.uk
www.mentalhealth.org.uk
www.mind.org.uk
www.nao.org.uk
www.nhs/pathways/dementia
enquiries@ic.nhs.uk
www.nice.org
www.statistics.gov.uk www.ons.gov.uk
www.who.org
www.opaal.org.uk
www.pr4ae.org
www.scie.org.uk
www.guardian.co.uk
www.kingsfund.org.uk
www.westminster-pct.nhs.uk/pdfs/bme

* Dementia North was part of the Dementia Services Development Centres Network but no longer exists
** these no longer exist

Publications
Developments in Dementia Advocacy, by Sally Wells. WASSR (2006)
Ethnic Diversity and mental health in London. (2003), King’s Fund. www.kingsfund.org.uk
Mapping Older Peoples Advocacy in the English Region by Dr Gary Kitchen OPAAL (2007)
Mental Capacity Act 2005 and Code of Practice www.dh.gov.uk
Mental Health Act (2007) and Independent Mental Health Advocacy (2009) www.dh.gov.uk
Mental health advocacy for black and minority ethnic users and carers in Trent and Yorkshire (2002), Joseph Rowntree Foundation www.jrf.org.uk
Speaking up for people with Dementia: Guidelines on providing advocacy for people with dementia, WASSR (1999)

Journals

Dementia Advocacy Newsletter dan@wassr.org
Community Care www.communitycare.co.uk/Articles
The Journal of Dementia Care, Hawker Publications www.careinfo.org
Living with Dementia: Alzheimer’s Society Magazine www.alzheimers.org.uk
Planet Advocacy: Action for Advocacy newsletter www.actionforadvocacy.org.uk

Appendix A1  The Demographics

The ageing population
The 2005 mid year population census estimates indicates there were 9.65 million people in the UK aged 65 and over. Of these 4.6 million were 75 and over and 1.18 million over 85. Women over 65 outnumbered men over 65, with 82 men to every 100 women. The greater number of women was

23
most pronounced among the very old. Life expectancy of a man of 60 was 80.5 years and of a woman of 60, 83.6 years.

Thirty year predictions are that the overall population will continue to age, with 25% of the population being over 60, 20% over 65 and 10% over 75. By 2031 it is expected that people over 85 will make up 3.8% of the population. The sex ratio is expected to change by 2031, with women over 50 outnumbering men over 50 at 90 men to every 100 women. Amongst those over 85 the ratio is predicted to be 65 men to every 100 women.

The minority ethnic population of the UK and England
The most recent (2001) UK census showed that 4.6 million people, 7.9% of the total population, were from non white minority ethnic groups. Information about white minority ethnic groups is hard to find but these include 691,000 Irish (1% of the total population). The highest concentration of minority ethnic groups was in London (45% of the total) making up 29% of all London residents. Main areas of concentration in England are indicated below, the percentages being the percentage of the UK total in that area. Non white minority ethnic groups make up 9% of the population of England and are concentrated in large urban areas.

| Distribution of BME groups across England as a percentage of all ethnic groups |
|-----------------------------|-----|
| London                      | 45  |
| West Midlands               | 13  |
| South East                  | 8   |
| North West                  | 8   |
| Yorkshire and Humberside    | 7   |
| North East                  | 2   |
| South West                  | 2   |

Not including the Irish and white European groups, the largest minority ethnic (ME) group was Indian, followed, in descending order of size of population, by Pakistani, those of mixed ethnic background, Black Caribbean, Black African, Bangladeshi, Chinese, then other ethnic groups. In summary about half of the non white population were Asian, a quarter Black (African Caribbean and other) and 15% from mixed ethnic groups.

London is home to the highest concentrations of people of African Caribbean and Bangladeshi origin, whilst West Midlands, Yorkshire & Humberside and the North West is home to high concentrations of people of Pakistani origin.

WASSR's BME clients include people from Ireland and other European countries.

Age and Gender profile
White groups have an older age structure than BME groups, with about 18% of White British and 25% of Irish living in the UK aged over 65 years old.

The age structure of non-white groups reflects past large scale immigration patterns. Black Caribbean has the largest proportion of people from BME groups over 65 years of age (11% of people of Black Caribbean origin). The next highest percentage of people over 65 is found in people of Indian origin (7% of people of Indian origin), then in descending order Chinese, Pakistani, Bangladeshi and Black African. Black African and Mixed Race groups have the youngest age profile.

Progressive ageing is expected in all BME groups, the extent and rate of this will depend on fertility levels, mortality rates and future net migration.

Differences in mortality rates result in women aged over 65 outnumbering men in this age group. This is the case for all White groups in the UK with 58% of all people over 65 being women and for Mixed Race groups (55% over 65 are women) Chinese groups (54% over 65 are women). However in most other BME groups men outnumber women in the 65+ age groups. This is particularly the case in the
Bangladeshi group with only 34% of the over 65 population being women and the Pakistani group with 45% of people over 65 being women.

General Health issues relating to BME groups
We are a multicultural society. People have different beliefs, values, traditions and histories, all of which affect their choices in life and their responses to health issues.

Whilst differences between the White British and BME populations are reported, research into the overall health of BME groups compared with the health of the White British population has proved to be somewhat inconclusive. This makes it difficult to confirm that BME groups experience more problems than others as a result of their ethnic origin. Research does show however that low income and poor housing have a detrimental affect on the health of communities. A proportionally higher number of people from BME groups are from disadvantaged and poor communities, so it follows that a higher than average proportion will have poorer health and lower life expectancy.

There are known to be extra barriers experienced by BME groups when accessing services. These include the obvious factors such as language barriers and cultural differences and the less obvious such as lack of knowledge of services and not understanding that it is appropriate to use services. A lack of appropriate cultural awareness amongst practitioners means it is less likely people from BME communities will receive all the help they need.

A perceived "cycle of prejudice" is also thought to exist, with users thinking the service will not be appropriate and providers thinking the service will not be accepted. Older people are particularly likely to be affected by these many barriers.

As a result of these barriers people from BME groups are more likely to delay seeking help than their White compatriots. Language difficulties and cultural misunderstanding also lead to an increased risk of misdiagnosis. It is also thought that people from African Caribbean groups are treated differently by service providers because they are seen as more violent, in spite of the fact that statistics indicate the reverse is true.

Research has shown that Black African Caribbean groups have a higher than average number of people with high blood pressure and as a result are more likely than other groups to have a higher proportion of people with dementia.

It appears that mental health issues for people from BME groups are particularly likely to go unnoticed by medical practitioners. The Government has attempted to address this and some of the differences mentioned above through the plan to deliver race equality in mental health services. This plan calls for: better, more responsive services; better engagement of services with their local community; better monitoring of ethnicity; better dissemination of information and good practice; improving knowledge about effective services. Primary Care Trusts have been set targets for the recruitment of community development workers for BME mental health.
Appendix A2  Dementia in the UK

Historically dementia has suffered from the dual stigmas of mental illness and old age. This has led to poor public understanding of the disease and cause for concerns over the lack of professional understanding and provision of appropriate services. A recent survey of GPs showed that nearly a third did not think they had enough training to diagnose and manage dementia.

Over the ten last ten years voluntary sector organisations have progressively focused on the needs of people with dementia. Largely as a result of pressure exerted on government by these voluntary sector support groups, the will to address the needs of people with dementia and their carers has moved up the political agenda.

In addition current initiatives indicate the political will to adopt a holistic and integrated approach to the management of older people’s health. The intention is to make services “user centred” and adopt a case management approach to the provision of health and care services. There is also a stated intention to involve voluntary organisations in this provision and to ensure access to advocacy for those who need help when expressing their views in relation to the provision of these services.

Recent reports include the quote “dementia care is where cancer care was 50 years ago”. For many people with dementia, support is only available at crisis point, by which time it is often too late for the person affected to make his or her own decisions. Nearly a third of people with dementia wait three or more years for a diagnosis and about a sixth are never diagnosed. Without diagnosis there is no access to specialist dementia drugs and services.

The Government recently published the National Dementia Strategy (2009) with the objectives of transforming dementia services, raising public awareness of the disease and improving research into the causes of and treatment for dementia.

Two thirds of people in the UK with dementia live in the community and are cared for by 476,000 informal carers as well as through statutory care in the community. 64% of people living in care homes have some form of dementia. Older people occupy approximately 60% of hospital beds and of these it is estimated that 40% may have dementia. It follows that 24% of all people who occupy hospital beds may have dementia.

In 2007 it was estimated there were 700,000 people with dementia in the UK, of whom an estimated 11,000 were under 65 (early onset dementia) and 11,500 (1.6% of all people with dementia) were from BME groups. 6.1% of people with dementia and from BME groups had early onset dementia. 560,000 people with dementia lived in England. Two thirds of people with dementia were women.

The proportion of people with dementia doubles for every 5 year age group, for example 12.2% of all 65 - 94 years olds had dementia whilst 33% of people over 95 years had dementia. As the population ages, so the number of people with dementia increases. In 2006 there were 9.7 million people in the UK over 65, 1.2 million of these being over 85. The number of people over 65 increased by 31% between 1971 and 2006, from 7.4 to 9.7 million and this trend is expected to continue. As a result of population aging current estimates are that the number of people with dementia in England will rise to 750,000 by 2020.

Dementia in people over 65 costs the NHS £3.3 billion per year and the overall economic cost is estimated to be over £14.3 billion per year (more than stroke, cancer and heart disease combined). The average time from diagnosis to death is 11 - 12 years but diagnosis is often made late. The average time between the onset of symptoms and seeking help is 30 months, however a recent survey found that 27% of people with dementia waited three or more years for a diagnosis and 17% never received a diagnosis.

Early diagnosis is cost effective. Without diagnosis there is no access to specialist dementia care and drugs. Appropriate treatment can postpone high dependence on carers and improve the quality of life for people with dementia and their carers. However there are many barriers to early diagnosis, for example fear and ignorance of the disease preventing people seeking help and a perception amongst some members of the medical profession that little can be done. There is also some evidence that diagnosis is
often poorly communicated and some health professionals lack knowledge of the services and support available.

Some key dates

1997  WASSR obtained funding to pilot a dementia advocacy project and this led to development of expertise in this field and contributed to the birth of the concept of non-instructed advocacy.

2001  The Department of Health set out standards of care for people over 55 in the National Service Framework for Older people. This included standards for mental health care and for the early diagnosis of dementia.

2002  The Audit Commission's report Forget me Not found GPs slow in diagnosing and addressing the disease.

2003  WASSR obtained funding to set up a national network of people working in dementia advocacy.

2004  Department of Health provided funding to develop this and it became the Dementia Advocacy Network (DAN).

2005  Department of Health produced a Service Development Guide for Older People's Mental Health and commissioned an exercise to map services across the country.

2005  Mental Capacity Act passed.

2006  Department of Health report A New ambition for Old Age acknowledged that mental health services for older people were not adequate.

April 2006  Department of Health added a minimum requirement for GPs to record and review cases of dementia, albeit in the voluntary Quality and Outcomes framework of GP's contracts.

Oct 2006  WASSR published "Developments in Dementia Advocacy" which explores the role of advocates in supporting people with dementia: It was launched at WASSR's first national conference for dementia advocates.

Nov 2006  National Institute for Health and Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE) produced Supporting people with dementia and their carers setting out best practice for the care of people with dementia and the support of their carers.

Feb 2007  The Alzheimer’s Society published a major study on the social and economic impact of dementia in the UK. As a result of this study the society called for: “dementia to be a National Health and social care priority”, an increase in public funding for research; improved dementia care skills; developments in community based support and in carer support; a debate on who pays for care; development of comprehensive integrated care models.

April 2007  The Mental Capacity Act (2005) was implemented, giving statutory rights for people without capacity to be represented by an advocate. This would include some people with dementia. By definition the people covered by the act cannot instruct the advocate, so this has led to further development of the concept of non-instructed advocacy. The Act provided for the creation of Independent Mental Capacity Advocates (IMCAs) to deliver this advocacy.

Mid-2007  First meeting of the All-Party Parliamentary Group on Dementia. At the time the chairman said “dementia is one of the biggest health and social care challenges the UK faces, but more needs to be done to highlight its significance. Our vision for the group is to provide a force for driving the condition up the political agenda.” The Alzheimer’s Society has acted as secretariat to and carried out research for this group.

Aug 2007  The National Audit Office (NAO) produced a report following their examination of health and social care services in England for people with dementia and their carers.

Aug 2007  Government announced a project to produce the first National Dementia Strategy. The Care Services Minister recognised that the current system was failing too many people with dementia and their carers. He announced a determination to bring the disease out of the shadows and create an environment where people are able to seek early support, knowing they will get expert help and be treated with dignity and respect. He acknowledged the low level of public and professional understanding of dementia.

Nov 2007  Age Concern called for improvements in dementia support, particularly focusing on mandatory dementia training for care staff.

Dec 2007  Government announces a social care reform concordat Putting People First. The main thrust is to personalise care and provide this care in an integrated way. The concordat
recognises that people are living longer and increasing numbers will be living longer with chronic conditions such as dementia. It is an attempt to begin to meet the challenges of providing social care and independent living into the future through partnerships between all statutory and non-government providers of services. The introduction to the concordat specifically mentions the need for every individual with a personal budget and those utilising direct payments to have access to advocacy and support according to their particular needs. A Green Paper was to be published in 2008.

2007

The Care Service Improvement Partnership (CSIP), as part of the Older People’s mental health programme, produced resource material for people with dementia for commissioners of services and for practitioners.

2008/9

The Healthcare Commission has proposed a National Clinical Audit of dementia. This is seen as an important development, with the potential to achieve a step change in awareness and understanding of dementia.

May 2008

Alzheimer’s Society launched a public information campaign Worried About Your Memory to raise awareness of dementia, its symptoms and the importance of early diagnosis.

Sept 2008

2009

The Department of Health held a public consultation on a National Dementia Strategy. The Department of Health published the National Dementia Strategy with the intention to spend £150 million over two years to improve dementia services and awareness. The key elements of the strategy are to ensure early diagnosis and intervention, improve the quality of dementia care and raise public awareness. The strategy also aims to address health inequalities relating to dementia.

April 2009

Statutory access to an Independent Mental Health Advocate (IMHA) is now available to patients subject to certain aspects of the Mental Health Act 1983 (including people with dementia.) IMHAs are an important safeguard that will help and support patients to understand and exercise their legal rights. IMHAs will be available to most adult patients as well as patients on supervised community treatment or guardianship.
Appendix A3  Dementia amongst BME groups

Recently the Royal College of Psychiatry identified a "research gap" in dementia amongst BME communities. The anecdotal evidence from people interviewed as part of this evaluation supports this and also indicates a gap in more general information relevant to the experiences of older people from BME communities.

It is known that 6.1% of all people diagnosed with dementia and from BME communities have early onset dementia, compared with 2.2% of all people with dementia. However this difference may be a result of low overall levels of diagnosis amongst BME groups, clinical differences or a combination of factors.

England has a higher proportion of people from BME communities than other parts of the UK, so an assumption that there are between 10,500 and 11,000 people over 65 with dementia from BME groups and resident in England would be reasonable.

Assuming a figure of 10,500 an estimate of the numbers in each area can be found by using the percentage distribution of BME groups across England. Please note this does not take into account any geographic or differing age profiles of BME groups or the increased susceptibility of some groups to high blood pressure, leading to possible higher levels of dementia.

<table>
<thead>
<tr>
<th>An approximation of numbers of BME elders by region</th>
</tr>
</thead>
<tbody>
<tr>
<td>London 4,725</td>
</tr>
<tr>
<td>West Midlands 1,365</td>
</tr>
<tr>
<td>South East 840</td>
</tr>
<tr>
<td>North West 840</td>
</tr>
<tr>
<td>Yorkshire &amp; Humberside 735</td>
</tr>
<tr>
<td>North East 210</td>
</tr>
<tr>
<td>South West 210</td>
</tr>
</tbody>
</table>

It is difficult to find any information directly relating to experiences of people with dementia from BME groups. However, taking the experiences described in the section above on general health issues and looking at this in the light of the identified barriers to early diagnosis of dementia, it is clear that people from BME communities are likely find it particularly difficult to deal with the disease and all its implications.

The specific differences identified by research include the following:
- BME groups take above average time between onset of symptoms and seeking help
- The needs of the family may be different to the needs of white British families;
- South Asian families have less specific knowledge of dementia and see the disease as part of the ageing process. Consequently it is difficult to raise awareness of the disease or undertake research within this community, as in many languages there is no word for dementia
- BME groups are more likely to think care should be provided by friends and family;
- African Caribbean people are more likely to experience high blood pressure, so more likely to be susceptible to dementia.
- It is acknowledged that, when communicating with people with dementia who do not have a good understanding of English, there is a need to do more than translate the words for them. Appropriate health and care services require an understanding of the history, culture and development of the patient's community.

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### Appendix A4 Summary of work by EMDAP to support Advocacy and BME Community Organisations

<table>
<thead>
<tr>
<th>One to one support for organisations</th>
<th>Group work (presentations/training/awareness raising /workshops) for Greater London organisations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Greater London organisations:</td>
<td>Advocacy in Barnet</td>
</tr>
<tr>
<td>The Advocacy Project - Learning Disabilities in Camden, Kensington &amp; Chelsea and Westminster</td>
<td>Age Concern Camden</td>
</tr>
<tr>
<td>Al-Hassaniya Moroccan Women’s Centre</td>
<td>Alzheimer’s Concern Ealing</td>
</tr>
<tr>
<td>Centre for Armenian Information and Advice</td>
<td>Asian Women’s Resource Centre - N London</td>
</tr>
<tr>
<td>Chinese National Healthy Living Centre</td>
<td>Centre for Armenian Information and Advice</td>
</tr>
<tr>
<td>Inclusion Project</td>
<td>EKTA project – Asian elders - Ealing</td>
</tr>
<tr>
<td>Eastwards Trust Saati Resource Centre</td>
<td>Hillingdon Carers</td>
</tr>
<tr>
<td>Haringey Asian Day Care Centre</td>
<td>Iranian Community Centre in London</td>
</tr>
<tr>
<td>Iranian Community Centre in London</td>
<td>Kurdish Association in West London</td>
</tr>
<tr>
<td>Kingston Advocacy Group</td>
<td>The Latin American Elderly Project</td>
</tr>
<tr>
<td>Latin American Elderly Project</td>
<td>Muslim Cultural Heritage Centre</td>
</tr>
<tr>
<td>Persian Care Centre in London</td>
<td>Persian Care Centre in London</td>
</tr>
<tr>
<td>QALB Day Care Services</td>
<td>Westminster &amp; Kensington &amp; Chelsea BME Health Forum</td>
</tr>
<tr>
<td>Sierra Leone Community Group</td>
<td>Westminster &amp; Kensington BME Health Forum</td>
</tr>
<tr>
<td>SUBCO Trust, East London</td>
<td></td>
</tr>
<tr>
<td>Sudanese Women Empowerment Group</td>
<td></td>
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<tr>
<td>Vietnamese Mental Health Service</td>
<td></td>
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<tr>
<td>Westminster &amp; Kensington BME Health Forum</td>
<td></td>
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<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>One to one support to organisations outside London</td>
<td>Age Concern Slough and Berkshire East</td>
</tr>
<tr>
<td>Advocacy in Somerset</td>
<td>Alzheimer’s Society Leicester</td>
</tr>
<tr>
<td>Advocacy Network Ipswich</td>
<td>Bangladeshi Mental Health Association -Birmingham</td>
</tr>
<tr>
<td>Advocacy Network Leeds</td>
<td>Chinese Community Centre &amp; Trent Housing - Support for Older People</td>
</tr>
<tr>
<td>Dorset Advocacy</td>
<td>East Suffolk Advocacy Network</td>
</tr>
<tr>
<td>East Suffolk Advocacy Network</td>
<td>Just Advocacy, Suffolk</td>
</tr>
<tr>
<td>Just Advocacy, Survey</td>
<td>Leeds Jewish Care Services</td>
</tr>
<tr>
<td>Leeds Jewish Care Services</td>
<td>People’s Voices In Milton Keynes</td>
</tr>
<tr>
<td>People’s Voices In Milton Keynes</td>
<td>Princes Royal Trust Carers Centre, Bristol</td>
</tr>
<tr>
<td>Princes Royal Trust Carers Centre, Bristol</td>
<td>Southend Advocacy Service</td>
</tr>
<tr>
<td>Southend Advocacy Service</td>
<td>User Support Services – Northampton</td>
</tr>
<tr>
<td>User Support Services – Northampton</td>
<td>Watford Asian Community Care</td>
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<tr>
<td>Watford Asian Community Care</td>
<td></td>
</tr>
</tbody>
</table>

### Group work to organisations outside London

<table>
<thead>
<tr>
<th>Advocacy with national networks</th>
<th>Action for Advocacy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Afya Trust</td>
<td>Age Concern England</td>
</tr>
<tr>
<td>Migrant Resource Health Centre</td>
<td>BME Elders Forum and national BME Networks</td>
</tr>
<tr>
<td>NAN Conference</td>
<td>NAN Conference 2008</td>
</tr>
<tr>
<td>National BME Advocacy Network</td>
<td>National BME Advocacy Network</td>
</tr>
<tr>
<td>PRIAE - Policy Research Institute on Ageing and Ethnicity</td>
<td>National Dementia Advocacy Network Conference 2006 and 2009</td>
</tr>
<tr>
<td></td>
<td>OPAAL/Good Advocacy Practice</td>
</tr>
<tr>
<td></td>
<td>PRIAE - Policy Research Institute on Ageing and Ethnicity</td>
</tr>
</tbody>
</table>
Appendix A5  Feedback from interviews with people working in organisations.

The researcher interviewed two separate groups of people about their experience of EMDAP activities and of working in the field. These were people working in advocacy organisations and people working in BME community organisations.

1. People working in advocacy organisations

Nineteen advocacy project workers from nineteen advocacy projects were interviewed by researcher Jill Jones. Most had attended one or more EMDAP workshops or training sessions.

The advocacy projects in more detail

All projects covered in the interviews provide advocacy for older people, but the focus of that advocacy varies widely from project to project. A significant number deliver IMCA, but many of these also undertake general advocacy whilst some work specifically with people with learning or physical disabilities. Projects working with clients in or moving into residential care (in addition to IMCA work) were also well represented, including some providing financial management services, help dealing with solicitors and estate agents and help to find the best home.

Some of the projects providing general advocacy for older people have specialist workers, for example to work on financial abuse issues, mental health issues or carer issues. Only one interviewee was working as a hospital advocate and also providing crisis intervention and one provided advocacy for older prisoners and service users of direct payments.

Many said working with older people with dementia is becoming a major part of their work, but only one has a project exclusively for people with dementia, offering group work and the facility to refer on those needing individual advocacy. Four projects providing general advocacy extended their service to people of any age living with dementia and a number of projects have specific dementia advocacy workers. One organisation previously had a dementia advocacy project, but the funding has recently ceased.

When asked about the number of clients with dementia only one respondent said none, “as we refer them on”. Five said a few, the remainder either said it was a major part of their work, or gave percentages between 35% and 85% of clients. Four indicated clients often have multiple difficulties which include dementia.

None of the people interviewed work for providers with a specific Black and Minority Ethnic (BME) project. Two said “we had one but the funding ceased”. Nine said they had clients with dementia from BME communities and these gave the number of these clients as either “one” or “very few”. In more rural areas this was seen as representative of the local population, although some concern was evident for Roma and Eastern European communities. All interviewees in urban areas thought that the number of clients from BME communities and with dementia is significantly under representative. One organisation in the London area has a high number of advocacy clients from BME communities, but very few of these have dementia. Organisations in areas with significant BME populations are usually able to access interpreters, but all commented that this is expensive.

Two of the advocacy organisations use volunteers for volunteer advocacy or for volunteer partnerships, which they described as a sort of cross between befriending and advocacy.

The EMDAP Workshops

Most people interviewed said they found the workshops stimulating, useful and interesting. They reported that they gained a better understanding of the problems of supporting people with dementia and from BME communities. The need for a flexible, sensitive approach with a good understanding of relevant cultural issues and word of mouth communication, is the message that most people took away.

Participants liked the format of the workshops and the knowledge café approach adopted. They appreciated the opportunity to network, share experiences and ideas. Some were able to get input from
others to help with specific problems they faced in their work with BME groups.

Many spoke of gaining a better understanding of the extra problems facing people with dementia from BME communities and quoted topics such as misdiagnosis and negative attitudes to the illness. A few said they would like to have spent more time looking at different approaches to different ethnic groups and to have met more people from a variety of BME groups.

A significant number of participants stated that they have used the knowledge gained at the workshops in their subsequent work. Five have or are in the process of specifically targeting BME communities.

After attending the workshop the feeling that "you are not alone" is important to many. Also the support given by the project worker since attending the workshop has been felt to be invaluable to those seeking help to set up BME dementia advocacy work. Many participants keep the literature to hand for reference and said that they now use what they learnt in their day to day work.

This quote typifies the general feedback about the workshops.

"I found it very positive and exciting. I knew I could apply what I was learning. There was a lot of information and support. I have done some BME outreach since the workshop."

Feedback about other information disseminated by EMDAP
Those interviewed said the information from the workshops was useful and that the project worker has been a great help but some were not so aware of the information from the EMDAP sent out by email.

Comments on the experience of working with BME groups
All respondents have some experience of working with people from minority ethnic groups, although not necessarily with dementia or in their current work. There were many comments made about this and these are summarized below, listing the ones most frequently made.

"There are so many barriers - language, non verbal communication, history, cultural background, protocols. In some groups there is a stigma attached to dementia. BME people with dementia don't get listened to and don't understand."

"Appropriate interpreters are needed - especially with Asian groups. The Interpreter needs to understand the same language, culture, medical terms, be independent, be trusted by the client. An Interpretation service is expensive."

"It is possible people from BME groups are more likely to be sectioned for their own safety, as a result of communication and cultural differences."

"In IMCA advocacy we come across dementia a lot. With BME clients we need to work at a slower pace, use different (eg pictorial) methods, look for clues, expect a time delay between question and answer, sort out major assumptions made by other health care professionals. Sometimes the client says yes to everything because they want to be seen to understand or want to please, or no to everything to protect themselves. Generally they are terrified."

" Advocacy is not seen as a part of the doctor's toolkit."

"We need to find ways to get round the white middle class image of our provision - making the service accessible to all ethnic groups. Different cultural groups often don't know a provision exists."

"We need to look at each target group in its own right, to recognise the many different cultural implications and protocols. To meet the needs of many different language speakers. All this is very expensive."

"BME groups traditionally seek services in their own communities, are insular and don't feel the mainstream services provided are for them. It is possible referrers do not refer BME clients to us (the
advocacy service) because we do not have advocates with the client's cultural background. There are only small groups of BME people in rural and some urban areas. These small groups are even less likely to be catered for."

"Amongst some BME communities there has been an expectation that children will care for their parents, but young people are now working, so this expectation is not realistic. However there may be a reluctance to put relatives in a care home because of cultural issues, for example around food and washing. Care worker training is needed."

"Fewer BME people are returning to their homeland in retirement. As a result there will be an increased need for BME dementia care and advocacy."

"BME groups are under represented in care homes - why? Very few of these are referred to advocacy services and we (the advocacy service) rely on referrals. It is very difficult to find appropriate care home places for people from BME groups."

"There are a lot of care workers from BME communities it would be good to have time to see if they have issues around understanding the needs of residents."

"There is a low level of awareness of BME people's needs amongst professionals, including social care teams and hospital staff and little recognition of the different strategies needed to work effectively with BME clients."

"Cultural awareness training is needed for all health and care workers. Cultural problems and taboos can make many services inaccessible to BME groups."

"We thought saying "access was for all" would mean BME communities would use us. This is not the case. We now know we need to do a lot of work with local groups to make this happen. Working with BME groups is very hard to get off the ground. Other things are more easily done and use fewer resources, so are more likely to be allocated funds."

"We tried to research BME needs locally, but this didn't work because feedback from groups was not forthcoming."

"We need to get into the BME communities, raise awareness of dementia and show it isn't a problem families have to struggle to deal with alone. This is a long slow process, often leading to high frustration on both sides. Often a lot of discussion takes place, but it doesn't seem to move forward and become action. We need to understand cultural differences and how these relate to expressing wishes and needs effectively."

"With IMCA a lot of clients have dementia and some are from BME groups. As an advocate I often only meet the client once when there is a specific decision to be made (e.g. around accommodation or serious medical treatment) and meet only with people who have no friends or relatives to help. I can refer on to further advocacy - but there are no resources locally. I would like to do more."

"The public has very little understanding of dementia or advocacy. It is hoped the new (independent advocacy) qualifications will help with the recognition and understanding of advocacy."

"Trying to provide advocacy in a hospital setting with no privacy is very difficult. This would be almost impossible with a client who does not speak English."

The Advocacy Projects' Aspirations
Seven of the people interviewed work in organisations which are planning new or increased work targeting BME communities. Although not necessarily targeting people with dementia specifically, the nature of these advocacy projects is such that they will be providing dementia advocacy.

Other aspirations include setting up a collective dementia advocacy project and a scheme to link people in care homes with appropriate services (which would be of help to BME groups).
Other organisations deal only with referrals, so their client group depends upon who is referred. And others are already working to capacity so cannot increase their caseload, or have funding problems so that survival is their main aspiration.

Training
The information on training collected through the interviews was rather sketchy, but it is clear that larger organisations are more likely to undertake systematic and wide ranging training. Several of these regularly review what they do and devise and deliver in-house training.

Other sources of training provision include Age Concern England, the Alzheimer’s Society, WASSR and DAN, the Action for Advocacy website, local Community Mental Health Teams and other statutory agencies. A few mentioned local solicitors and Fast Forward Training for committee members and lead workers.

One person commented that their equality and diversity training did not cover how to reach BME clients and there was no specific diversity lead in the organisation nor were there funds to cover this.

Funding
Many projects are struggling to find funds and seven are unsure of their immediate future. Only five projects seem to have reasonably secure funding, all funded by the local authority and/or health trusts: most have some form of contract. These organisations see the statutory funding as a measure of their success. Some of the remainder have statutory funding, but this is either reducing, coming to an end or not secure. Six projects have funding from Comic Relief and/or the Lottery, some in addition to statutory funding. This type of funding is time limited and most were near the end of three year funding periods. A few projects obtained some funding or help in kind through other trusts and/or because they were part of Age Concern.

Continuity of funding is a major difficulty and many said that there is a need to break away from the culture of one off and time limited funding for “flavour of the month” projects. It was also felt that it was difficult to develop services that take a significant amount of time to develop the expertise and networking essential for success and expertise, because most funders want “measurable outcomes” in too short a time span. Providing dementia advocacy to BME elders cannot be achieved with a “quick fix”.

Some interviewees said funders expect outreach and work with BME communities, but with regard to those with dementia it is numerically more productive to concentrate on general advocacy for older people from minority ethnic communities or through IMCA. One person said it is impossible to get additional funding for work with BME groups in affluent areas or areas with a low percentage of BME residents.

Promoting the service
In the main it was reported that clients are referred or introduced to projects by the statutory services, by other voluntary organisations such as Age Concern, by word of mouth or by providers of other support services. Some will come through an IMCA referral. Many of those providing general advocacy said that word of mouth was the principal way in which their clients heard about them. Few do much promotional work, mainly because they are already working at capacity or their future funding is uncertain.

General experience is that hard to reach groups seldom respond to promotional efforts. The best way to make contact with them is through existing groups or by using someone who really understands the target culture.

There is a perceived need for wider education amongst the younger generations in BME groups, covering dementia and the services available.

General comments from interviewees
“We have a very simple and informal referral process which means we are used in preference to other providers.”

“We work with clients with multiple issues, so we tell funders the length of time we take must be open
ended: we cannot measure success by numerical outcome."

"We could do with more training so we can recognise and understand how the affects of different types of dementia differ."

2. Feedback from interviews with people working in BME organisations

Nine people were interviewed, representing nine different BME projects, for example women’s groups, lunch clubs and community centres. Most interviewees had attended an EMDAP awareness session or a dedicated workshop with members of their organisation.

Key comments about the dementia awareness raising sessions
All the people interviewed said the awareness raising session was very good, well received and understood by the audience as it was given in the group’s language (some via an interpreter).

It is evident that prior to the talk many group members were unaware of the symptoms of dementia, the services available and the relevant English words used. The workshop or presentation was recognised as a unique opportunity to get information and ask questions in the audience’s native language.

Group workers reported that they have used the knowledge they gained to signpost people to services and to be more alert to the symptoms of dementia and ways to help people affected by dementia. Some said it also helped them improve their more general skills - particularly the need to listen to people.

Awareness of the prevalence of dementia within their group
Of the nine people interviewed, five said either there were no people, or they did not know of any people, in their group with dementia. Three said some had dementia and one said dementia was prevalent. Most commented that they did not think there was any information on the prevalence of dementia in their communities.

Comments about and specific problems around dementia faced by their communities.
The overriding view is that dementia is very frightening and the fear is exacerbated when the person affected is in a foreign country. Interviewees saw a need to encourage their communities to be more open and to discuss the issues. Some commented that there are many services available in Britain and this may not be the case in their homeland. Encouraging discussion and openness would help their communities to access these services.

Interviewees reported a scarcity of statutory help to link people from minority ethnic groups with health and social care provision in a way that ensures mutual understanding. The sense was that a “take it or leave it” attitude exists in the statutory sector.

Many people from BME communities rely on the goodwill of friends, relatives, community groups and community workers to provide any extra support needed. Most people interviewed said their communities tended to keep dementia “in the family” and there is an expectation the family will provide care. This puts a lot of strain on family and community resources, some people slip through the net and many probably never receive a proper diagnosis. In some communities dementia is seen as shameful, so the norm is for a family not to openly admit that one of its members might have dementia.

One Asian group leader said older people expect others to care for them even when they are capable. They can become lazy and often don’t bother with the hassle of interpretation. It was felt that it was important for resources to be available in the client’s language and to promote independence amongst the older generation.

Other issues mentioned included: the inappropriate use of children to act as Interpreters; Issues around proper training and health and safety provision for community/health/care workers who may be asked to help because they understand a person’s culture; older people with multiple needs which have not been recognised early; the total lack of experience of dementia amongst people from BME communities with a younger age profile.
Gaps identified by the people interviewed
The main gap identified was the need for two-way awareness raising to help BME communities gain a better understanding of dementia and to help service providers understand the needs of the specific BME groups with whom they work.

The community group workers interviewed recognised that they are often the first to spot problems. They suggested more training to help them in this task, coupled with more information and resources in a wider range of languages. They also see the value of intergenerational work and public awareness raising within their own communities.

There was a universal call for more sharing and co-ordination between statutory authorities, voluntary and community groups. This needs to be both in respect of individual cases and in co-ordinating work across agencies to improve the chances of early diagnosis.

Advocacy for people with dementia is not available to many BME communities. Advocates need to have a thorough understanding of the language and culture of that community for the service to be accessible.

None of the people interviewed knew of any sources of information about the prevalence of dementia in their specific community.
Appendix A6  Identified gaps in provision

A number of gaps were identified as a result of the survey of BME community group leaders and advocacy providers who have attended EMDAP workshops.

1. Absence of advocacy provision accessible to BME elders
   Very few older people with dementia and from BME communities have access to specific advocacy services. If advocates lack a thorough understanding of the language, history and culture of that community, advocacy will not be accessible to the older members.

2. Training needs
   There is little comprehensive and ongoing training for advocates working with people with dementia and from BME groups. Advocating for people from BME communities needs to be included in the diversity training of advocacy providers.
   Specific training needs for advocates identified were:
   - How to find, make contact with and work with the specific minority ethnic communities likely to be encountered by the trainees;
   - how to recruit volunteers and access other help from BME communities – and especially to assist with gaining access to those communities;
   - dealing with multiple health issues, including dementia, for people from specific BME groups;
   - how to work with interpreters and people with dementia;
   - how to involve the families of BME clients with dementia.

   Training for BME community group workers and others is needed and is particularly important as such workers are often the first to spot problems. It is needed in areas such as:
   - advocacy skills,
   - ageing and dementia awareness,
   - supporting people with dementia,
   - the services available and relevant systems

   Training for health and social care professionals in working with people from BME groups and with dementia is also needed.

3. Awareness Raising
   Work is also needed to address the gaps identified in knowledge and understanding of dementia and BME communities.

   Nationally: promotional/educational work about living with dementia and that dementia is a health issue. Extra effort is needed to reach BME communities and to include community education to raise awareness amongst older people, families and the younger generation.

   For BME community groups: awareness training in understanding dementia and the services available for people with dementia. There is especial need for community workers, volunteers and potential volunteers from BME communities to be made aware of the value of advocacy for people with dementia and from their communities.

   For service providers: there is a need for awareness training both in understanding the needs of the BME groups they work with and the fact that advocacy is available to support service users.

   For funders: work to educate and change attitudes so that they are more willing to recognise the needs of people with dementia and from BME communities and to recognise the need for sustained funding.

   Beyond awareness training there is a need for campaigning to encourage early diagnosis with a focus on the needs of people from BME communities.

4. Resources
The following resources and information are scarce and/or difficult to find:
- Relevant numerical/statistical information - both locally and nationally.
- Specifically information on the prevalence of dementia in specific BME communities.
- Information to illustrate how dementia is seen and tackled in the home country and how cultural background impinges on a person’s experience of dementia.
- Relevant printed, audio, audiovisual and on line material in a wide range of languages and individually tailored for professionals, community workers, families and older people.

It would also be beneficial to have easy access to:
- Materials such as the results of research, case studies, “how to” approaches, for use by advocates and advocacy projects working with people from BME communities.
- Ways to pool and share information from and with other advocacy providers.
- A template for undertaking local research to get the information needed to support funding applications.

5. Further Research
The work to date has shown the absence of hard data around dementia and people from the BME communities. Research is needed
- To establish the extent to which BME needs around dementia advocacy are not being met and why this is so.
- To identify and evaluate the different models and approaches to reaching and advocating for BME communities.
- Around the residential care needs of BME people with dementia - why are they underrepresented in care homes, is anything needed to address this.
- To establish why there are few referrals of BME clients with dementia to advocacy projects.
- To find out how best to get feedback from BME people with dementia.
- An action research case study project on advocacy work with BME people with dementia in care homes.
- A complete “case study” from start of project to referral of significant numbers of BME clients with dementia, to illustrate effective ways to outreach and provide advocacy for BME groups.
- A case study to evaluate the effectiveness of collective advocacy for people in the early stages of dementia and from BME communities.
- A pilot project (with case study) to improve the link between older people with dementia from a specific community and the local health and social care agencies.

6. Co-operation
Some gaps were reported that hinder effective sharing and co-ordination between statutory agencies, voluntary and community groups.
Appendix A7 Overcoming barriers and meeting the challenges of the project

In the following section the barriers and challenges experienced in delivering the project are in italics, followed by comment on the way in which these were addressed.

1. Many BME and Advocacy project workers are part time and their hours do not overlap, so co-ordination is not easy. It was difficult to meet the demand for support in a part time post. The project was resourced for 3 days a week. At a later stage WASSR found the resources to extend this to 4.5 days a week and has meant that support to advocacy services and community groups has been provided more effectively.

2. The project worker’s own need for training in dementia advocacy. The project worker initially concentrated on learning about dementia through literature, from dementia advocate colleagues and through working with BME elders with dementia. Activities such as helping with the delivery of Introduction to Dementia training, developing this training for BME groups and preparing material such as power point presentations have reinforced this learning.

3. Making services accessible to a wide range of groups / the difficulty of making contact BME groups have been identified through the internet, through local publications and networking on a local and national basis. The project worker has attended local and national conferences and these provide good opportunities for finding contacts. Once groups are identified they have been sent information about the DAN and about the EMDAP. Training given to other advocacy providers includes information about how to find and network with local BME organisations.

4. Designing and tailoring the training and workshop sessions to meet different circumstances. Training sessions have been designed or adapted to meet the particular needs of each organisation. For example the workshops and information sessions for BME groups are very different from those for dementia advocacy providers. Sessions are varied in length and content. Feedback from the attendees, new information or learning experiences have all been used to enhance training material.

5. The many language and cultural differences encountered Workshops, training sessions and resource material are now available in a variety of languages. The project worker has direct experience of a range of different cultures and is aware of the need to adopt a sensitive approach to less familiar cultures. Indeed this is an important aspect of the training for advocacy providers developed by the EMDAP.

6. Promoting the concept and value of advocacy to BME group: the need to encourage those within BME groups to become advocates. This has been addressed by promoting the concept of advocacy directly to a number of different ethnic groups and by including elements on advocacy and advocacy standards in training sessions on dementia and memory loss for BME workers. In addition the project worker has had articles published in local BME community health newsheets and regularly conducts workshops for the DAN and for other national conferences.

7. Addressing the low level of knowledge about dementia amongst BME groups / communities not seeing dementia as a high priority All presentations to and contact with BME groups or workers have been aimed at raising awareness of dementia and address the generally low level of knowledge about dementia and the services available. Particular effort has been made to engage directly with groups of older people and to provide material in a number of different languages.

The project worker has designed and used training exercises to help illustrate the barriers to BME communities in accessing services and to illustrate the different, often unhelpful perceptions of both dementia and advocacy. Secondary research has been undertaken to begin to identify different perspectives on dementia in other countries and cultures.

Providing the opportunity for BME groups to learn about dementia, confront associated issues, share their experiences and ask questions has played an important part in the process of raising the priority of dementia amongst BME communities.
8. Incorporating the BME focus into the DAN and attracting people from the BME communities to the DAN
Workshops on outreach to and working with BME communities have frequently been included in DAN meetings and plans are in place to provide this opportunity at all meetings. Relevant articles have been published in the DAN newsletter.

As a result of contact with the EMDAP twelve BME groups have become members of the DAN, with consequent access to information and training relevant to the provision of dementia advocacy.

9. Finding and giving information on funding sources / lack of funding for groups
BME groups are particularly likely to suffer from lack of funding and the EMDAP has provided subsidised training for some of these groups. The EMDAP, through WASSR, has in the past been prepared to give some assistance in identifying sources of funding and by reviewing a group’s funding application. There are no financial resources to undertake relevant pro-active work.

10. Finding ways to improve uptake of the training and avoid last minute cancellations
Working in partnership with other support organisations has been key to improving the uptake of training. Improved and targeted promotional leaflets, better planning of the work needed to deliver and follow up information about training, flexible fees with concessions for BME community organisations have all helped to improve uptake of training.

11. Finding new ways to work with members of regional advocacy networks.
Through participation in national and regional events the project worker has built up contacts in the regions. By concentrating on previously hard to reach areas new contacts have been made and workshops delivered or planned in these areas. DAN meetings with associated EMDAP input have been held in a number of regions.

12. Ensuring that DAN meetings are welcoming and accessible to BME members.
Information about DAN events has been emailed to BME and other groups, however this is limited to 40 DAN member organisations with BME interests. This practice is to be reviewed in early 2009. Also under review are the needs of BME members and potential members of the DAN, in relation to the themes of the meetings.

13. Adapting DAN meetings and training to meet the needs of newly joined BME members
The training programme for 2009 includes Introduction to Dementia, Dementia Awareness for BME Groups and Communication Skills, all topics thought to be attractive to BME workers and people working with BME groups. The project worker is currently undertaking a training needs analysis (to be completed in May 2009) for workers working with BME people with dementia.
Appendix A8  Some good practice guidance on ensuring that dementia advocacy is accessible to BME elders

1. Be aware of potential barriers from the BME community

BME elders and their families may be
- Concerned about protecting their cultural norms and values
- Have a tradition of keeping problems within the family
- Fearful about developing a bad reputation within a community because of mental health issues
- Unfamiliar with using written information
- Unaware of their rights and entitlements
- Lack understanding of the UK health and care systems and have different expectations

Contributing factors may be
- Some BME communities have extra tolerance for suffering and inequalities
- People may have had unpleasant experiences with “authority” through their experience of exile, persecution and discrimination.
- Loss of community, history and traditions leaves people without context within which to exist and have a sense of belonging.
- There are different perspectives and understanding of advocacy and issues such as dementia, mental health and learning disabilities across different countries and cultures.
- In many cultures there is often not a particular word for advocacy and there is confusion between advocacy, advice, practical support and befriending.
- Some specific groups such as people with learning disabilities, mental health issues, dementia, domestic violence etc carry a stigma in many cultures so will often be unacknowledged or hidden away. This may prevent families from seeking help. Close family members will keep the problem away from the community at the beginning to avoid being labelled as a “family with mental health problems”. In some communities this could affect their marital affairs.
- Language barriers may prevent older people from accessing available services. Even if there is information in other languages many BME older people have limited levels of literacy even in their own language
- Even within the same culture or community the generation gap, education and class will often have great influence on attitudes and opinions.
- BME elders may be unfamiliar with social care services, perhaps because these services do not exist in the country they come from.
- Many older people from BME communities have strong religious beliefs that influence their lifestyle, customs and networks. Such beliefs may be very positive but may also create barriers to accessing services, especially when not understood by service providers.
- There may be stereotyping and assumptions made about service providers, by the BME elder or other members of the family because of unpleasant experiences when using the service in the past. This may be seen as discrimination or racism and can result in services being refused.
- There are different health problems amongst different communities
- Isolation and depression is very common amongst BME elders
- Older people from many BME communities can age faster than others due to past traumatic experiences, for example of war, exile and bereavement.
- BME elders often experience poverty and poor housing which themselves act as barriers.

2. Barriers from the service provider may be

- Lack of appropriate interpreting services. Here there are issues of “time limiting, availability, confidentiality…”
- Discriminatory and racist attitudes and stereotyping which lead to fear, or lack of trust in services.
- Lack of effective outreach and information providing accessible leaflets in appropriate languages,
outreach, effective networking with local BME groups to help with word of mouth information.

- The isolation that may exist between a community and the wider society
- Lack of understanding and unfamiliarity on the part of the service providers with the service users’ lifestyle, health, religious and cultural needs. This may lead to ineffective assessments and lack of sensitivity to the individual’s needs.
- Lack of suitable services where the person’s language is spoken and their cultural, religious and dietary requirements are met.
- Assumptions and stereotyping by service providers about the older person’s culture and perspectives especially when it comes to accessing mainstream services.
- The use of family members or a community member as Interpreters may compromise confidentiality or influence the assessment and cause even more distress to the older person with mental health or dementia.
- Older people from BME communities with Dementia and/or mental health issues may face triple discrimination because of their ethnicity, age and disability.

3. Practical and realistic methods of making advocacy accessible through outreach work include:

- Recruiting bilingual volunteers from the communities the service wants to reach.
- Holding advocacy surgeries in community groups and centres where the language and cultural needs of the person is met
- Employing bilingual advocates and BME outreach workers
- Using Interpreters and try to use the same person for all sessions
- Printing leaflets in different languages and getting them out to the communities
- Providing free training on topics such as advocacy skills and dementia awareness, in a venue local to the BME communities
- Finding out about the local BME networks, organisations and community groups
- Recognizing and attending BME communities’ special celebrations, a good opportunity to hand out leaflets and build relationships
- Making BME community groups and group leaders aware of your services and sending them up to date information.
- Starting to form simple partnership working with individual local BME organisations and groups
- Investing time in understanding different culture and backgrounds
- Visiting and learning from advocacy services that have developed positive partnerships with BME communities
- Including the cost of accessibility and BME outreach in your future plans and funding bids

4. Build the skills of your advocates to be able to work effectively in a culturally diverse environment. To do this they need

- Awareness of diversity and equality
- To challenge the double discrimination of racism and ageism experienced by Individual BME older people
- To promote Integration and facilitate access to culturally appropriate services
- To work to empower BME older people and their carers to Identify their own needs and develop culturally appropriate ways to meet them
- To ensure good communication with BME elders: this includes awareness of the importance of non-verbal communications such as eye contact, expressions and gesticulation.
• To avoid prejudices and stereotyping. Advocates should not make assumptions based on the client's cultural background, instead they should ensure that the needs and wishes of any individual client are established within the wider context of their specific situation.

• Advocates should take into consideration the cultural and spiritual backgrounds, language and gender of the client.