Culture and Care in Dementia

A Study of the Asian Community in North West Kent

Dr. Viniti Seabrooke & Alisoun Milne
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We would also like to thank Alzheimer’s Concern Ealing, for providing the video ‘Dementia Ki Hai’ and in particular, Kulbir Gill for her expert advice in supporting this project. Finally, we would like to thank the many service users and carers who willingly shared their stories and experiences to make this project worthwhile.

Viniti Seabrooke
Alisoun Milne
The Asian population in the UK is ageing and increasing numbers of older Asian people are developing dementia. Yet their uptake of mainstream services remains very low. The need to provide culturally appropriate services is pressing. Also pressing is the need to raise awareness among Asian communities that the quality of life of dementia patients and their carers can be greatly improved, by accepting help and taking up services from local providers.

The project described in this report focused on the specific needs of the Asian community in North West Kent. This enabled the project to reach Asian elders and their families, care workers, GPs and other related professionals to build a detailed and revealing picture of dementia-related need and the conceptualisation of dementia in the Asian community, and identify ways forward in providing appropriate dementia care.

But the findings in this report will have powerful resonance far beyond the local area. One of the specific aims of the National Service Framework for Older People is to facilitate early diagnosis of dementia, as it ‘gives access to treatment, allows planning for future care, and helps individuals and families come to terms with the prognosis’. Yet only now are policy and service planners beginning to consider the dementia-related needs of Asian communities. The backdrop is complex and the task challenging.

Meeting these needs will require a coherent, focused, multi-agency approach, designed to educate, inform, engage and ensure access to appropriate services. Working in partnership with Asian communities is absolutely key to the success of the approach, including Black and minority ethnic workers and service providers.

It is time for us as a society to develop a much stronger overall focus on early intervention in mental illness and other chronic disease; not just to treat illness but also to maximise people’s ability to live dignified lives and enjoy basic rights.

Through its expanding programme of work around mental health & later life, the Foundation hopes to continue investment in ethnicity and dementia research and service development. This project represents an excellent start to this work. The Foundation extends its gratitude to the highly skilled project researcher Viniti Seabrooke, for her dedication to the project, to the Alzheimers & Dementia Support Services Charity and in particular Carol Smith for supporting and ‘housing’ the project, and to Alisoun Milne, for her research expertise.

Dr Andrew McCulloch
Chief Executive
The Mental Health Foundation
Executive Summary

Section 1: Introduction

This report outlines a research project to explore the service related needs of Asian older people with dementia and their carers in the Dartford and Graveshaw area of North West Kent (NW Kent). It was conducted over two years from February 2002 to January 2004 and was based at Alzheimer's and Dementia Support Services (ADSS), a local dementia care charity. The project was funded by the Mental Health Foundation.

National Context
The under-representation of ethnic minority populations in dementia services is a long standing concern of researchers and service providers. Service development is only now coming to terms with the fact that the populations that immigrated in the 1940's are ageing and require dementia care.

Since the Audit Commission Forget-me-Not reviews of mental health services for older people, and the implementation of the National Service Framework for Older People, the Government requires the National Health Service and local councils to develop protocols for the diagnosis, treatment and care of all patients in their area with dementia. This includes older people from ethnic minorities.

There is also a growing body of research evidence in this arena. This includes work on: the needs of Asian family carers, how dementia is differently conceptualised in Asian communities and deficits in mainstream and minority ethnic services.

The Ageing Population and Prevalence of Dementia in South Asian Populations
The UK population is ageing. By 2016 there will be nearly 1.8 million ethnic minority elders (Age Concern England, 2001).

As longevity is the most important risk factor for developing Alzheimer's disease - the most common form of dementia - the incidence of dementia is increasing in all ethnic groups, including the Asian population. Some Asian populations are also at enhanced risk of developing vascular dementia due to the increased incidence of diabetes and hypertension.

The Local Context
Nearly 70% of the ethnic minority population in NW Kent reside in the Dartford and Graveshaw area. Census data evidences that the Asian population forms the single largest ethnic group; most are of Punjabi Sikh origin.

This community first established in the 1940's as a result of active recruitment by the British Government to offset post World War 2 labour shortages. The first settlers came from farming families in Punjab, North India. Recently, the area has seen an influx of Asians from the Midlands and the North. Community members tend to be close and know each other well.

Section 2: Aims and Methods

Aims
The project’s key aims were to:
• investigate the nature of dementia related need amongst older people from the Asian community and their families
• determine why so few Asians currently use dementia services
• explore what kinds of services they need and
• raise awareness and knowledge about dementia.

Methodology
The project had the dual purpose of collecting data for a research project, which would inform service development. As an exploratory study it drew primarily upon action research and qualitative methods. These included semi-structured interviews, workshops and focus groups. Data was analysed using a content analysis technique and categorised using a grounded theory approach.
Section 3: Stages of the Project

The project was conducted in four stages. The first focused on ‘Making Links and Mapping Services’ with the Asian community and services, the second - ‘Exploring the Dementia Related Needs of the Asian Community’ - incorporated the fieldwork, and the third and fourth stages involved the presentation and analysis of findings.

Section 4: Findings and Discussion

Mapping Services
Although a small number of older Asians use mainstream dementia services, particularly hospital care, the key facilities accessed are those provided for Black and minority ethnic populations. The most popular and ‘acceptable’ service is day care for frail Asian elders. Whilst this is culturally appropriate, it is not resourced to support people with dementia.

Mapping the Dementia Related Needs of the Asian Community
Semi-structured interviews were conducted with a cross-section of respondents: a sample of GPs, service providers and carers, also a telephone survey of care homes. These were supplemented by a number of educational and awareness raising workshops, which attracted a large mixed group of participants including community members, older Asians, carers and workers.

Understanding of Dementia
One of the most striking findings of this project was the lack of knowledge and understanding of dementia in the Asian community. They do not conceptualise the illness as an organic disease or treatable illness. Asian languages do not have an equivalent word for dementia.

There is an almost universal negative perception of dementia; in its early stages, it is often regarded as a ‘normal’ part of ageing. This perception, coupled with the lack of knowledge about treatment and services, acts as a powerful barrier to both users and carers seeking support.

Cultural beliefs also play a role. Asians place great emphasis on the importance of being self-sufficient, portraying an image of well-being, and hiding mental health problems. Confidentiality is also an issue, especially in a close - and rather separate - community. Considerable stigma is associated with acknowledging dementia.

Diagnosis of Dementia
Recognising the symptoms of dementia is widely noted as a prerequisite for diagnosing and treating dementia in its early stages. Early detection is particularly important for those at risk of vascular dementia because underlying physical causes are often treatable. The fact that many Asians come to the attention of services at an advanced stage of dementia severely limits opportunities for preventive treatment. Carers also tend to seek help later, which creates higher levels of stress and reduces quality of life.

The lack of willingness amongst many Asian patients and their families to acknowledge dementia, coupled with the pressures of the average GP workload, undermines the facilitation of early diagnosis. Additionally, there are often language problems and standard ‘tests’ may not be culturally appropriate.

Service Provision
Service providers in the area are keen to support an initiative to improve access to, and quality of, dementia care for older Asians and their families. This includes addressing the barriers between the Asian community, service commissioners and providers. Overall, participants attribute the low uptake of services to a mismatch between the linguistic, cultural and religious needs of the Asian community and provision.

Specific barriers to service usage amongst Asians are: lack of knowledge about dementia and services, cultural differences, communication and language difficulties, fear of breach of confidentiality and stigma. A lack of knowledge among service providers and managers about the lifestyles, health, religious and cultural needs of Asian people is also a barrier. This raises the importance of training.

Services developed for the Asian community and those that employ Asian staff are accessed more readily and are viewed as more appropriate by older Asians and their carers. Medical services are also more acceptable than ‘mental health’ or ‘social care’ services.
Very few care homes have Asian residents. There is some evidence to suggest that placements do not proceed as a consequence of homes not being able to accommodate the linguistic and dietary needs of older Asians.

Support Needs of Carers
Even though carers in the study were under enormous strain, they were unwilling to relinquish their caring role due to a commitment to family duty.

The few services that were acceptable include long-term hospital care and day care. There is widespread condemnation of placing a relative in a care home. Many respondents commented on the need for carers to have respite breaks.

Inter-generational Conflict
Several respondents noted the increasing level of conflict between the expectations of the older generation and the aspirations of their younger second generation offspring. The resultant clash of cultures has undermined family bonds, assumptions about inter-generational reciprocity and traditional support structures. This includes a trend towards younger adults no longer remaining in the parental home post marriage.

Raising Awareness about Dementia
The study evidenced the positive role and value of awareness raising and educational workshops. The importance of balancing a need to take account of the cultural and linguistic milieu whilst offering clear information about dementia and services cannot be overemphasised. Offering workshops in different settings to a range of audiences, over a significant period of time was also useful.

Section 5: Implications for Service Development

The ‘Culture and Care in Dementia’ project makes it clear that neither the Asian community nor service providers in NW Kent are satisfied with current provision for older Asians with dementia or their carers.

In addition to sharing a common identity and culture with a service and/or its staff, other important issues include: ease of access, greater availability of culturally appropriate day and respite care and a greater level of awareness amongst service providers about the lifestyles, health, religious and cultural needs of older Asians and their carers. Although it is appropriate for new services to be integrated into existing provision, it may be necessary to provide separate services for the current generation of older Asians.

So far service planners have tended to be reactive to the needs of Asian carers; they need to become proactive and tackle the underlying issues of resistance. Much work still needs to be done to educate and inform the community about dementia, treatment and services, as well as address barriers to service usage. If service planning and commissioning is to be sensitive to the needs and beliefs of the Asian community it is crucial to work in partnership with key members; this includes older people with dementia, their carers and service providers, particularly Asian staff. Whilst existing plans for additional dementia services are positive, there remain considerable deficits in the support system for older Asians with dementia and their families.
Culture and Care in Dementia: A Study of the Asian Community in North West Kent

Section 1: Introduction

This report outlines a research project undertaken on behalf of Alzheimer’s and Dementia Support Services (ADSS) and the Mental Health Foundation to assess the needs of Asian older people with dementia and their carers within the Dartford and Gravesham areas of North West Kent (N.W. Kent). The work was carried out over two years from February 2002 to January 2004 and was funded by the Mental Health Foundation as part of their Dementia Research Initiative Programme. The project was based at ADSS, a registered charity and the lead provider of practical and emotional support for local people with Alzheimer’s and other dementias and their carers. The work was commissioned as a result of concern about the lack of uptake of dementia services by the local Asian population and the awareness of a lack of knowledge about the needs of this group in relation to dementia services.

The report is presented in five sections. Section 1 offers the context for the project, Section 2 identifies the project’s aims and methods, Section 3 outlines the stages, Section 4 describes and discusses the research findings and Section 5 explores the implications of these for services and dementia care for the Asian community of NW Kent.

This first Section ‘sets the scene’ by offering a:
• review of the national policy and research context
• summary of the dementia prevalence amongst the Asian population in the UK and
• introduction to the location and context of the research study.

The National Policy Context

In 1989, the White Paper ‘Caring for People’ recognised that people from different cultural backgrounds have particular needs and that, since minority communities may have different views of what constitutes ‘community care’, it is important that service providers are sensitive to these variations (Department of Health, 1989).

In 1989, the Social Services Inspectorate published a report entitled ‘They look after their own, don’t they?’, which challenged the myth that ethnic minority families universally support dependent members and highlighted a number of service deficits (Department of Health, 1998). The inspection of community care services for Black and minority ethnic (BME) older people in eight local authorities acknowledged the genuine attempts by social services departments to provide services to minority ethnic older people, but found that the services were not necessarily culturally appropriate and were marked by a distinct lack of choice: ‘... the variety of services available offering choice to Black elders was limited and the Eurocentric nature of service provision meant many Black elders had difficulty in having their needs met’ (Department of Health, 1998).

In 1990, the ‘National Health Service and the Community Care Act’ provided a framework for major changes to the delivery of health and social care to vulnerable older people (Department of Health, 1990). It provided an opportunity for the statutory sector to engage with the independent sector and work in partnership with service users and carers to identify their needs and develop services to meet them. After coming to power in 1997, New Labour invested in a programme of modernisation for health and social care. A key plank of this was ‘The NHS Plan 2000’ which required NHS trusts and social services departments to define how they will meet the health and social care needs of local populations (Department of Health, 1998a). The development of comprehensive partnerships between social services, health agencies, communities, service users, carers and the independent sector underpinned this initiative. It also placed particular emphasis on meeting the needs of marginalised and minority groups and ensuring equality of access to services, particularly for vulnerable adults, including those with dementia. This is reinforced by a specific focus on the needs of minority ethnic older people by the Department of Health (Department of Health, 2002). Specific attention was paid to mental health services for older people and their carers by the Audit
Commission ‘Forget-me-Not’ reviews of 2000 and 2002. These highlighted considerable variation in range and types of services and a lack of coherence in dementia care; they also identified a dearth of specialist services for ethnic minorities (Audit Commission, 2000, 2002).

In 2001, the ‘National Service Framework for Older People’ was published; Standard 7 of this document relates specifically to older people’s mental health care (Department of Health, 2001). The aim of Standard 7 is to promote good mental health in older people and to effectively and appropriately treat and support those older people with dementia and/or depression. The Standard states: ‘Older people who have mental health problems need access to integrated mental health services, provided by the NHS and councils to ensure effective diagnosis, treatment and support, for them and their carers.’ (Department of Health, 2001, p90).

The Standard also states that mental health services for older people should be able to respond effectively to individual needs, taking account of the social and cultural factors affecting treatment, recovery and support. The key interventions required for improving prevention, care and treatment of mental health problems in old age are identified as:
- promoting good mental health
- early recognition and management of mental health problems and
- flexible access to specialist care when required.

In relationship to older people from ethnic minorities, Standard 7 states: ‘Older people from Black and ethnic minority communities need accessible and appropriate mental health services. Unfortunately, for a number of reasons, services may be neither readily accessible nor fully appropriate.’ (Department of Health, 2001, p90 7.3).

The existing evidence base about South Asian communities is characterised by small studies exploring the needs of local populations and larger studies which include South Asian groups within a broader definition of ‘ethnic minority populations’ (Ahmed and Atkin, 1996; Atkin and Rollings, 1996; Bhugra and Bahl, 1999; Blakemore and Boneham, 1994). Material in this section is drawn from both types of studies.

**Care-giving in the Asian community**
The issues that commonly emerge from work on care-giving in Asian communities are: the significant role of religion in underpinning the prominence of family care, filial responsibility, the stigma associated with mental illness and a need to contain the person with dementia within the family, hidden from the wider community (Daker-White et al, 2002). The fact that formal responsibility for care tends to reside with a male relative and that actual care is delivered by female relatives, usually daughters or daughters-in-law, managing care alone, is also widely noted as is the fact that Asian carers appear to experience very similar levels of stress and ‘burden’ as their white counterparts (Chryssanthopoulou & Milne, in press). Further, the strongly held myth that ‘they look after their own’ continues to be articulated in the literature (Adamson, 2001; Department of Health, 1998; Patel et al, 1998). This is interesting in light of the fact that there is increasing evidence that changes to the ‘traditional’ profile of Asian families now mean that many older people live alone, with younger adults moving away for work and not being available to support their parents (Ahmed, 1996).

**Understanding of Dementia**
One of the most serious challenges associated with developing appropriate responses to older Asians with dementia is the use of terminology and the conceptualisation of dementia by the Asian community (Braun and Browne, 1998; Dilworth-Anderson and Gibson, 1999, 2002). The word ‘dementia’ does not exist in any of the Asian languages; it is simply termed ‘pagal’, a term meaning ‘mad’ and no distinction is made between organic and functional mental illness.

The Research Context

Of equal significance to social policy is the role and relevance of research. The NW Kent project was informed and influenced by existing research evidence about:
- how dementia is understood in Asian communities
- dementia services and support needs and
- good practice.

...
Dementia is recognised as a particular form of madness linked to ageing and as such is ‘natural’ and ‘untreatable’. Further, it is associated with stigma and shame (Milne 2002, 2003).

Another significant issue relates to early detection and diagnosis. Evidence suggests that early intervention can delay progression and improve the symptoms, function and quality of life of those affected (Milne et al, 2000; Wilkinson and Milne, 2003). This is particularly the case for those with a potential diagnosis of vascular dementia, as this is one of the few types of dementia for which remedial risk factors exist. Early diagnosis of dementia generally starts at home with the recognition of symptoms by the person themselves or their relatives.

Little attention has been paid to the conceptualisation of dementia by South Asian families in the UK (Rait et al, 1996; Sabat, 2001). This is an important omission as, together with the implications for potential treatment, carers understanding of dementia has been linked to coping with caring (Graham et al, 1997).

Services & Support Needs
The under-representation of people from ethnic minority groups in dementia services has been noted by both researchers and service providers (Badger et al, 1988; Brownlie, 1991, Brownfoot and Associates, 1998). Only now are policy and service planning systems beginning to consider the dementia related needs of Asian communities (Heer, 2001; Patel et al, 1998; Daker-White et al, 2002).

Reasons for under-utilisation of services include:
• differences in dementia prevalence rates
• cultural deficiencies in the instruments used to assess cognitive function
• differing cultural perceptions of the signs and symptoms of dementia
• a younger age structure
• the stigma attached to mental illness
• a lack of knowledge about services and
• a general reticence to use health and social services stemming from a belief that they are culturally inappropriate.

Language issues, particularly in the case of first generation migrants, have also been highlighted as an issue. One consequence of these barriers is that older Asians with dementia tend to come to the attention of services at a late stage of their illness when little can be offered by way of preventive treatment or support (Bowes and Dar, 2000; Katbamna et al, 1997).

Family carers of older Asians with dementia also appear reluctant to seek formal support; even those supporting relatives with very advanced dementia tend not to receive any input from services (Atkin, 1992; Baxter, 1988). This appears to be due to family and community resistance to getting help from ‘outsiders’ as well as the reasons already identified (Da Silva, 2001). Fear of services is particularly acute for ‘psychiatric’ or mental health services; generic services such as primary care or day care for physically frail elders are more acceptable (Patel and Mizra, 2000).

Although there is much debate about whether it is better to invest in developing specialist services for Asian elders, this specific issue remains unexplored in research. What is clear however is that older Asians want services they can ‘rely on and that provide good quality care, preferably staffed by people able to meet the particular needs of users in terms of gender of carers, skin/hair care and diet’ (Adamson, 2001).

Services specifically developed for the Asian community that are staffed by people who speak the same language as the older person, serve culturally appropriate food and take account of religious and cultural practices and festivals are particularly valued by care-givers (Department of Health, 1998). In the US it has been demonstrated that where mainstream services have matched users with staff according to ethnicity and language, user outcomes are improved (Braun and Browne, 1998). Manthorpe (1994) has argued for specialist reminiscence services for Asian elders who tend not to speak English or revert to their language of origin when they develop dementia.

Patel et al (1998) have conducted a review of services and research in three European countries. They argue that the service solution lies in investing in community minority ethnic organisations to provide dementia services.

They further suggest that these need not become exclusive and should aim to meet the needs of a mixed group of users and carers.
There are of course considerable differences between communities and situations (Milne, 2003; Lampley-Dallas, 2002). For example in Ealing, West London where the well integrated Asian community has existed since the 1940’s, older Asians with dementia access mainstream services as well as specialist dementia services and services developed specifically for the Asian community. However in most areas of the UK, Asian communities tend to be geographically and/or culturally isolated and do not use social services; primary care and hospital care services are more acceptable although under-used in relation to dementia (Shadlen, 2002).

**Good Practice**

There is a limited evidence base focus on ‘good practice’ in dementia care for Asian elders. One issue relates to the importance of outreach work to underpin service development; as older Asians are under-represented in dementia services and each Asian community has particular needs this is an essential pre-requisite (Hinton, 2002). It is vital to employ Asian staff who speaks the same language(s) as the community and to engage with community leaders, service commissioners and planners, local policy makers and practitioners. To house the outreach activity in a local ‘trusted’ service is also useful.

In terms of what makes for an effective service ‘system’ the following appear significant:

- developing services that take account of local conditions
- training staff to be culturally sensitive and aware
- regularly running workshops on dementia awareness for community members and
- ensuring that older Asians are offered timely assessment of cognitive function using appropriate diagnostic instruments (Powell, 2002; Stewart, 2002).

Research suggests that carers value advice and information about benefits and services as well as day care and respite care. The challenge is not only to ensure these are delivered in a culturally appropriate way but that carers are identified and helped to make use of services at an early stage in the caring trajectory. Specifically offering educational workshops to families is one approach that helps engage carers (Obkuyiga, 1998).

**Researching the Needs of Asian Communities**

Evidence identifies a number of challenges associated with researching the needs of Asian elders, particularly in the arena of dementia. Reasons include:

- reluctance on the part of community members and families to come forward to take part in a project
- a 'lack of fit' between the Western view of dementia and that held by the majority of Asian communities and
- limited understanding by the white dominated ‘research community’ of the barriers facing Asians in accessing and making use of services.

Even framing the research aims within a Western illness model may alienate potential participants and act as a barrier to engaging with the conceptualisation and experiences of older Asians and their families. This lack of connection is mirrored by the experience of services, many of which are unsuccessful in generating meaningful connections with older Asians with dementia or their carers (Dilworth-Anderson and Gibson, 1999).

**The Ageing Population and Prevalence of Dementia in South Asian Populations**

The increasing prevalence of dementia underpins the enhanced policy and research focus on dementia related services and care (Audit Commission, 2002). This is strongly related to the ageing population profile of the UK. Projections suggest that the number of people over pensionable age is likely to increase from around 11.2 million in 2006 to 11.9 million in 2011 and will rise to 13.1 million by 2021 (National Statistics Office, 2002). Within this overarching trend is an increase in the number of older people belonging to minority ethnic populations; by 2016 this number will be nearly 1.8 million (Age Concern England, 2001; Warnes, 1996).

As longevity is the most important risk factor for developing Alzheimer’s disease - the most common form of dementia - the incidence of dementia is increasing in all ethnic groups, including the South Asian population (Paykel et al, 1994). Surveys indicate that overall about 6% of those aged 75-79, 13% of 80-84 year olds and 25% of those aged over 85 have ‘case level’ dementia (Audit Commission, 2000, 2002).

Estimates suggest that there are currently more
than 750,000 people in the UK with dementia (Alzheimer’s Society, 2003). The rising costs of providing services is of linked concern with the annual direct costs of Alzheimer’s disease estimated to be between £7-15 billion (Dening, 2002).

Whilst specificity of prevalence of dementia within particular ethnic minority populations is limited, the Alzheimer’s Society has estimated that at least 5,000 older people from ethnic minorities have dementia (Alzheimer’s Society, 2003). The fact that this estimate was made in 1998, the relevant populations continue to age and the figure is likely to be an underestimate, suggests that numbers will be considerably higher now (Patel et al, 1998). It is useful to note that a number of South Asian groups are at increased risk of developing vascular dementia - the second most common form of the condition - due to enhanced levels of diabetes and hypertension (McKeigue and Chaturvedi, 1996; Department of Health, 2001). At present, as a consequence of original patterns of migration to the UK, there are more older men with dementia than women in the Asian population (Bowes and Dar, 2000).

Data from local studies is also relevant. One study in Bradford by Bhatnagar and Frank (1997), amongst the South Asian population, suggests a prevalence rate of 4% of dementia by ‘psychiatric diagnosis’ and 7% by cognitive function instrument.

Overall then the changing age profile of minority ethnic populations in the UK means that dementia will become a more significant issue in the future and demands for services greater (McCracken et al, 1997; Badger et al, 1988). The fact that older Asians tend to live within their communities, and that Asian communities tend to be concentrated in specific geographical areas, makes the impetus to develop robust and well founded local responses to dementia imperative. It is to the location of the research project described in this report that we now turn.

The Local Context

The Ethnic Profile of NW Kent

The 2001 Census shows that 3.1% (41,534 people) of the total NW Kent population (1,329,718) is of minority ethnic origin (National Statistics Office, 2001). The largest ethnic minority community (approximately 15,000) resides in the Dartford & Gravesham area where the ‘Culture and Care in Dementia’ project is based. About 80% are thought to be of Punjabi Sikh origin.

Map of West Kent

![Map of West Kent](image)

There are 5 main districts in the West Kent area and Dartford and Gravesham are the smallest of these, being only 66 out of a total of about 430 square miles. West Kent has a population of 502,524, which is fairly evenly distributed between the districts.

Population Distribution in West Kent 2001 Census

<table>
<thead>
<tr>
<th>District</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Tunbridge Wells</td>
<td>21%</td>
</tr>
<tr>
<td>Dartford</td>
<td>17%</td>
</tr>
<tr>
<td>Tunbridge &amp; Malling</td>
<td>21%</td>
</tr>
<tr>
<td>Sevenoaks</td>
<td>22%</td>
</tr>
<tr>
<td>Gravesham</td>
<td>19%</td>
</tr>
</tbody>
</table>

Ethnic Minority Population by District

<table>
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<tr>
<th>District</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tonbridge &amp; Malling</td>
<td>8%</td>
</tr>
<tr>
<td>Tunbridge Wells</td>
<td>11%</td>
</tr>
<tr>
<td>Dartford</td>
<td>25%</td>
</tr>
<tr>
<td>Sevenoaks</td>
<td>9%</td>
</tr>
<tr>
<td>Gravesham</td>
<td>47%</td>
</tr>
</tbody>
</table>

As is shown by Figures 2 and 3, nearly three quarters of the total ethnic minority population of West Kent is concentrated in Dartford and
Gravesham. The total population of this area is 181,628. Overall, 5.5% of the population of Dartford and 10.5% of the population of Gravesham is from BME groups. Data from the Census identifies that of the total of 8,154 Sikhs living in Kent, 6,379 reside in the Gravesham area (National Statistics Office, 2001). Other BME communities include African Caribbean, Muslim, Chinese, Hindu, Jewish, Mauritian, Turkish and Greek Cypriot (Kent County Council, 2002).

The national picture of an ageing population profile is also reflected in NW Kent. Whilst we know very little of the actual prevalence of dementia in this community, it is clear from the population profile already described that dementia - both Alzheimer's disease and vascular dementia - is a present and future issue which requires attention. The concentration of South Asians in the Dartford and Gravesham areas offers an opportunity to explore need at a local level.

**History of the Asian community in NW Kent**

A Sikh population has been established in NW Kent since the 1940's when the first immigrants arrived; they migrated as a result of active recruitment by the British Government, to offset severe shortages in the labour force following the Second World War. The early settlers originated from a few villages in the state of Punjab in North India where the small number of families knew each other well (Saheli Writers Group, 1994). They were primarily young males who intended to stay temporarily, achieve economic prosperity and return to India to support their extended families. They considered a trip to England to be an opportunity of a lifetime and a reality for only a lucky few. Thus, over a period of time, as these early settlers became financially secure, they chose to send for their friends and family members to share their good fortune. As a result, the community grew and became established. In fact, at one time it appeared as though the whole village, with its social order and relationships preserved, had been transported to Gravesend (Ilyas, 1998; Pamneja, 1997). Community members continue to be close and tend to know each other very well.

Most of the early migrants came from unskilled farming families and took up manual jobs in local factories. Although, over the years, many have moved on to more skilled occupations, the community is still largely working class. More recently, the area has seen an influx of Asians from the Midlands and the North of England; most have moved to NW Kent as a result of marriage. As the younger, second generation of immigrants have become adults and married partners from different backgrounds, their priorities, beliefs and values have changed. This change continues and is accelerating with particular implications for traditional support structures and family care relationships; it has also exposed a need for services for older people with long-term health problems.

Having ‘set the scene’ for the ‘Culture and Care in Dementia’ project, the authors move onto describing its aims and methodology.
Section 2: Aims and Methods

Aims & Objectives

This project’s principal aim was to investigate the needs of Asian older people with dementia and their carers in the Dartford and Gravesham area (the Study Area) and contribute to service development. Subordinate aims were to raise the profile of older Asians with dementia, enhance understanding among service commissioners, providers, and the Asian community, and inform the development of dementia-related services.

The specific objectives were to:

- Investigate the nature and extent of dementia among older Asians and the needs of family carers
- Determine why neither users nor carers access existing dementia services to any significant extent
- Identify the services Asian older people with dementia and their carers do currently access and what kind of support they receive and
- Identify the services needed to meet the needs of older Asians with dementia and their carers in the future.

Within the first two months of the project it became apparent that in order to achieve the project’s objectives, much work would be required to raise awareness about dementia and extend knowledge of the condition among older Asians, carers, and the wider community. Thus an additional objective was added, to:

- Raise awareness and knowledge about dementia.

Details of the original Project Plan written at the start of the project are given in Appendix 1.

Methodology

From the outset the project had the dual purpose of collecting data for a research study that would in turn inform service development. In order to achieve these aims, the project drew primarily upon action research methods (Patton, 1990). This is appropriate as it is exploratory in nature and its aims are to evaluate the needs of a specific population. It is also based in a community setting and requires engagement with a wide range of participants (Hart and Bond, 1995). In order to gather evidence about existing services and explore the views and perceptions of GPs, service providers, carers, and the wider community, a number of qualitative approaches were employed; these included semi-structured interviews, workshops, and focus groups (Bowling, 2002; Patton, 1990).

Mapping Services

A cascade approach was adopted to identify services relevant to older Asians with dementia and their carers (Bowling, 2002). This took the form of approaching a number of key agencies, known to the project researcher and ADSS, who then provided details of other services that were subsequently invited to take part. It also involved building up a network of contacts.

Sampling

In terms of sampling, existing networks and key advisors were consulted to identify health and social care staff. Carers were approached via ADSS. It was initially planned that a number of older Asians with dementia would also be interviewed. As the project progressed it became clear that this would be impossible as the majority using services are in the advanced stage of the illness and are not amenable to being ‘interviewed’ in the usual way. Gaining informed consent would also be very difficult. Further, it is likely that families would be reluctant to allow their relative to take part, as dementia carries a considerable stigma in the Asian community and tends to be hidden as far as is possible. These issues are picked up later in the report; it is important here simply to acknowledge their role in influencing methodological decisions.

Data Collection

Semi-structured questionnaires were employed to elicit the views and perceptions of GPs, service providers, and carers. The questionnaire themes were developed drawing on existing evidence about the topic, the aims of the research project, and the authors’ knowledge of Asian culture. The questionnaires were designed to encourage participants to express their views openly whilst ensuring that data was collected around a number of core issues (Bowling, 2002). Most data was gathered via face-to-face interviews although a small number were telephone interviews or self-completed questionnaires. Confidentiality was assured at all times. The questionnaire themes for GPs,
service providers and carers are outlined in Appendices 2, 3 and 4.

A key source of data was a programme of ‘Information/Awareness Raising Workshops’ and ‘Focus Groups’. The information obtained during the sessions was recorded from observational notes, which included both verbal responses and observations of tone, physical posture, expression and other non-verbal behaviour. Focus groups are successfully used to examine not only what participants think but also how they think and why they think in that way, their understandings and priorities (Kitzinger, 1995 & 1996). It is a specifically useful technique for exploring cultural values and beliefs about health and disease, such as understandings of dementia.

Data Analysis
All data was entered into Excel worksheets and then categorised using grounded theory and content analysis techniques; this enabled data to be structured and presented in a coherent and robust manner (Glaser and Strauss, 1967; Bowling, 2002). The analysis was iterative in nature. In addition to using some of the numerical data to prepare graphs of findings, quotes from participants were used to illustrate the themes that emerged and to add depth to the findings (Heiman, 1998).
Section 3: Stages of the Project

The project began in February 2002 with the recruitment of an Asian Researcher who was familiar with, but not actually from, the local community and was independent of statutory organisations in the Study Area. The researcher could speak Punjabi and Hindi and was responsible for the design, data collection, day to day management and reporting of the project. As noted above, the project was based in a small charity - ADSS, where the researcher could draw upon the local knowledge and dementia related expertise of the manager and staff. In addition, the project benefited from research supervision given by a Senior Lecturer in Social Gerontology at the University of Kent, who was also acting as a Programme Consultant for the Mental Health Foundation during the project period.

Although the project was originally funded for 21 months, an additional 3 months of funding was subsequently granted by the Foundation. Extra time was primarily needed as a result of:

- A greater level of interest and concern about dementia amongst service providers, older people from the Asian community, GPs and community leaders; this led to more time being spent discussing the project with individuals from these groups.
- The level of awareness of dementia among the community being very limited, more time had to be spent on raising awareness than had been anticipated. The information workshops proved to be more popular and fruitful than expected and often one workshop would lead to a request for another. As a result, more workshops had to be run over the course of the project.
- Attending service planning/commissioning groups and interviewing the full range of health, social care and voluntary sector agencies taking more time than was budgeted for. This also reflects cancellations at short notice of meetings as well as the project’s wider relevance.
- Persuading GPs to find time to take part in the study was particularly time consuming as many reminders, both written and by telephone, were needed to secure interviews.

The number of hours worked by the Project Researcher varied from 15 per week during the first nine months to 21 per week for the remainder of the two year period.

Stage 1: Making Links and Mapping Services

Publicity and Making Links
From the outset it was viewed as essential to raise the profile of the project in the Asian community, identify stakeholders and inform as many people as possible about the aims and objectives of the project. It was hoped that this would encourage participation and extend discussion about dementia.

The project was publicised in a number of ways and via a number of avenues (e.g. see Appendix 5.) Introductory leaflets were produced in Punjabi and English describing the project. These were widely circulated in GP surgeries, local libraries, Social Services Department offices, voluntary organisations and the Gravesend Gurdwara. All translated material was checked with Punjabi speaking staff and service users of the local Asian Day Centre (The Guru Nanak Day Centre). A prototype ‘Dementia Workshop’ was developed early on in the project to raise awareness.

Contact was made with the Gravesend Sikh temple (The Guru Nanak Darbar Gurdwara) to raise awareness through their local radio station; religious and information broadcasts are regularly made from the temple during the months of April and November to coincide with religious festivals. Two 20 minute sessions were broadcast, in English and in Punjabi, during which information on dementia and its effects on older people and their carers was discussed, along with information about the project and contact details.

In terms of agencies with a national or international remit, UK based Alzheimer’s and Dementia groups and the Alzheimer’s and Related Disorders Society, India (ARDSI) were approached. A Punjabi video ‘Dementia Ki Hai’ (meaning ‘What is Dementia?’) was obtained from Alzheimer’s Concern Ealing and posters and booklets were sought from ARDSI; all were used for publicising the project and raising awareness about dementia among the Asian community (Alzheimer’s Concern Ealing, 2000).
Service Planning and Commissioning in North West Kent

In order to raise the profile of the project and ensure the co-operation of key agencies, contact was made with a number of service planning and commissioning groups in NW Kent. The membership and structure of these changed during the project period, reflecting national policy changes and care priorities.

At the beginning of the project, NW Kent had a number of planning and commissioning groups that had a partial remit for developing services for older people with mental health needs from the Asian population. These included: the ‘Ethnic Health and Social Care Forum for Mental Health’ and the inter-agency ‘Information Sharing Group’. Additionally there was the ‘West Kent Strategy Group for Older People with Mental Health Needs’ and more locally the ‘Dartford, Gravesham and Swanley Older People with Mental Health Needs sub-group’. The project was introduced to members of these groups by giving short presentations at their meetings and giving out the introductory leaflets. Knowledge was also sought about the dementia related needs of the Asian community via these meetings and appropriate individuals for follow up interviews were identified.

By the end of the project, planning and commissioning systems had changed. Partnership arrangements between agencies had led to the merger of two mental health trusts - Thames Gateway and Invicta - to form the West Kent NHS and Social Care Trust. In addition, the West Kent Health Authority became part of the Kent and Medway Strategic Health Authority.

Specifically, service planning for meeting the needs of minority populations and older people with mental health problems became the responsibility of two groups. These are: ‘The Black & Ethnic Minority Health & Social Care Forum’ (as before) and the ‘Dartford, Gravesham & Swanley Joint Commissioning Board Mental Health - Sub-Group Older People with Mental Health Needs’. Strategically all commissioning decisions are now made by the ‘Whole Systems Capacity Planning Group’ to which the other groups link.

Mapping Services

A number of team meetings of statutory agencies were attended to inform health and social care staff about the project. Information was gathered about the range and type of services older Asians with dementia currently use and what services they and their carers want in the future. An initial meeting with an agency often led to several other useful links being identified.

Team meetings attended include:
- Social Services Older Peoples team in Dartford
- Social Services Older Peoples team in Gravesend
- GP sector meeting in Dartford, Swanley and Gravesend
- Elderly Care Forum meeting
- Admiral Nurses Meeting (Admiral Nurses support carers of people with dementia)

Written policy and related documents describing services and service deficits for Asians in NW Kent were also reviewed.

Stage 2: Exploring the Dementia Related Needs of the Asian Community

The Fieldwork

Several qualitative research methods were used to elicit information and the expression of views and opinions by a cross-section of respondents, whilst allowing them to influence the direction of the discussions. The fieldwork included discussions with staff from statutory and voluntary agencies, discussions with key members of the Asian community, in-depth face-to-face interviews, some postal questionnaires, a short telephone survey of some of the residential and nursing homes in the Study Area and focus groups with participants of some workshops.

Interviews with General Practitioners

Face to face interviews were held with seven general practitioners from six different surgeries in the area. Of these, four were male, three female; six were Asian and one was white. In addition, the researcher spoke to three other GPs at various meetings about their views on the dementia related needs of the Asian community.

Contact was made with general practitioners by writing to forty GPs in the Study Area. The project aims were introduced in a brief letter, which was accompanied by a project
leaflet. The GPs were asked to find time for a half hour interview to explore their views on the needs of older Asians with dementia and their carers and how these might be better met. Initial letters resulted in only two positive responses. After seeking help from the local PCT in targeting those GPs who see large numbers of Asian patients, four names were given which resulted in three more interviews. A further two GPs were interviewed as a result of persistence with letters and follow up calls.

All GPs were also sent extra copies of the project leaflets and were asked to either leave these in their waiting rooms or, preferably, pass them on to any patients who they thought might be willing to come to a workshop or, if appropriate, be contacted for an interview.

Interviews with Health and Social Care Providers
A total of 32 responses were obtained from a range of professionals. 20 of these were completed at the time of a face-to-face interview and a further eight were completed by individuals and sent by post following an initial meeting to explore their views. The remaining four were completed by service providers as a result of a telephone conversation with the researcher or at the request of another interested professional.

The following staff members were interviewed:
- Admiral Nurses (1)
- Care managers (3)
- Clinical psychologist (1)
- Community Psychiatric Nurse (1)
- Consultants (3)
- Managers of residential homes (2)
- Social services managers (3)
- Staff from voluntary organisations (8)
- Other health professionals (6)
- Other Asian staff from statutory organisations (3) (The NW Kent Race Equality Council, Home Care Services and a school)

Of those interviewed, 13 were Asian, one African Caribbean, one South African and 16 were white. Eight were male and 23 female. Staff from the voluntary sector included those providing services to older people and carers (e.g. Crossroads, Age Concern, Carer’s Support Service and ADSS) and also those specifically working with the Asian community (e.g. Rethink, the Kent Council for Addiction). However, despite many attempts to secure interviews and repeated reminders to complete the questionnaires, the project is lacking the specific input of some key service managers from Kent Social Services Department.

Interviews with Carers
The existence of Asian carers in the community was brought to light as the interviews with GPs and service providers progressed. Some carers made themselves known to the project as a result of the publicity, which included the project leaflets, dementia awareness workshops, and the radio broadcasts from the Gurdwara. Several of the carers interviewed identified themselves to the project as a result of information from health professionals, GPs and community workers.

In depth semi-structured interviews were held with seven carers. Often, more than one carer was present at the interview; the views of each of the carers were recorded but have been included in the data only once to reflect the number of cared for people in the community. For example, in one interview the main carer was present with his wife and daughter and all three had helped with the caring role and answered the questions; all their answers were recorded on one form. Four of the interviews took place in the carer’s home, two in the ADSS offices and one at the carer’s place of work.

All the carers interviewed were Asian; two of the main carers were male and five female. They were all from the Dartford and Gravesham area and had been living there for between 12 and 38 years. Three of the carers spoke fluent English, three spoke a little and one did not speak any. The interviews were all carried out in either English or Punjabi. Four of the carers had health problems themselves and these included anxiety, diabetes, arthritis and motor neurone disease.

Workshops and Focus Groups
Ten workshops were delivered over the course of the project to a total of 153 people (100 male; 53 female). In addition a presentation about dementia (including information on the project) was delivered to more than 40 people at the Sikh Gurdwara in Gravesend. This was delivered at a time when the temple had its own radio station on air and therefore it was also broadcast live. ADSS staff were available at the Gurdwara for a couple of hours after the session, to allow people who
may have heard the information an opportunity to discuss any concerns about friends, relatives or
themselves with the staff members.

Two of the ten workshops were delivered to the Chinese community to a total of 37 people. These were arranged at the specific request of members of a Chinese women’s group and were delivered in English with the assistance of an interpreter.

All the workshops and focus groups with the Asian community were delivered in Punjabi. These are detailed in Table 1.

Each workshop began by establishing the existing knowledge about dementia among the participants followed by a session about information on dementia and the video ‘Dementia Ki Hai’ (Alzheimer’s Concern Ealing, 2000). For the Chinese community, an English video produced by the Alzheimer’s Society ‘Dementia does not discriminate’ was shown (Alzheimer’s Concern Ealing, 2001).

In four of the workshops, which were focus groups, a half hour session of group work was included to obtain the views of participants around three questions:
• Is dementia the result of old age or disease?
• Why the stigma?
• What services/help would you like to see in place?

**Telephone Survey of Residential and Nursing Home Managers**
21 residential homes for older people in the local area were contacted in an attempt to find out if any Asian elderly people were accessing their services. The homes included those run by the local authority, private and voluntary organisations. Each manager was asked if they had any elderly Asians in the home at the time of the survey of if they had had any enquiries from Asians over the last year.

The next section focuses on the research findings and discussion.

**Table 1: Raising Awareness Workshops and Focus Groups**

<table>
<thead>
<tr>
<th>Venue</th>
<th>Workshop group:</th>
<th>Attended by:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Milan Day Centre</td>
<td>Asian elderly women’s group</td>
<td>12 female</td>
</tr>
<tr>
<td>Rethink</td>
<td>Asian carers group</td>
<td>3 female</td>
</tr>
<tr>
<td>Advocacy Forum*</td>
<td>Asian Mental Health Forum</td>
<td>3 male; 10 female</td>
</tr>
<tr>
<td>The Grand Project*</td>
<td>Asian mixed group</td>
<td>4 male; 20 female</td>
</tr>
<tr>
<td>Guru Nanak Day Centre</td>
<td>Asian elderly women’s group</td>
<td>23 female</td>
</tr>
<tr>
<td>Guru Nanak Day Centre</td>
<td>Asian elderly men’s group</td>
<td>20 male; 1 female</td>
</tr>
<tr>
<td>Guru Nanak Gurdwara*</td>
<td>Asian mixed group</td>
<td>9 male; 2 female</td>
</tr>
<tr>
<td>Denton Family Centre*</td>
<td>Asian retired men’s group</td>
<td>32 male</td>
</tr>
<tr>
<td>Guru Nanak Gurdwara**</td>
<td>Asian mixed group</td>
<td>40+ total</td>
</tr>
<tr>
<td>Chinese Group</td>
<td>Chinese women’s group</td>
<td>5 female</td>
</tr>
<tr>
<td>Chinese Community</td>
<td>Chinese mixed group</td>
<td>32 total</td>
</tr>
</tbody>
</table>

* These sessions were focus groups
**Presentation at the Gurdwara, which was also broadcast live on a local radio station from the Gurdwara.
Section 4: Findings and Discussion

In this Section of the report the findings of each stage of the research project are presented followed by a discussion. Although much of the data is drawn from individual interviews, the authors are confident that they represent a wide constituency of views. For example, in some voluntary organisations, the task of giving a face-to-face interview was delegated to one staff member who tended to present a synthesis of a range of views. Data from workshops and focus groups represent a cross-section of views from older Asians, family carers, service providers, community leaders and community members.

Each sub-section highlights those findings of most interest or relevance to the project aims. Key findings are noted in shaded boxes at the end.

Mapping Services

This section gives an overview of the current service provision for older people in the area and highlights the services that are more regularly accessed by older Asians with dementia. Services are provided and/or funded by a mixture of social services, health agencies and the independent, mainly voluntary, sector. It is important to note how willing service providers were to contribute to the project and how many felt frustrated at the lack of service development for older Asians with dementia.

The main social care provision for older people in the area is as follows:
• a range of day care and rehabilitation services
• occupational therapy services for major and minor equipment and adaptations
• permanent and respite residential care
• domiciliary services
• day care centres including the Guru Nanak and Milan Day Centres, both of which provide specialist day care for the Asian community
• services for deaf, partially deaf, blind and partially sighted people
• Social Services Care Management Teams with appropriate language skills and access to the Kent Interpreting Service and
• Social Services BME Community Development Workers

Services purchased from the independent sector include:
• residential and nursing home places provided mainly by the private sector
• Age Concern’s day care services
• domiciliary and bathing services
• meals services
• support for carers e.g. Carers Support Service, Dartford and
• specialist dementia services of ADSS

Housing services:
There are various sheltered housing schemes in the area, provided by the local authority and also one scheme that is exclusively for the Asian community. This scheme is known as Presentation House and is provided by the BME social investment agency - Presentation Housing Association.

Health services:
The West Kent NHS and Social Care Trust has two wards at Stone House Hospital in Dartford (Riverview and Thames Wards) that are designated for the care of dementia patients. Riverview assessment ward is a short stay ward (six-eight weeks) but often patients remain there longer due to a shortage of long-term care places in the area. Thames Ward is the main dementia ward in the area and has places for 19 long stay patients. The project found three Asian patients with dementia who had been there for several years.

There is also a day hospital facility (Hornbeam Day Centre) for older people at Darenth Valley Hospital. No Asian patients were found at this facility.

The main facilities accessed by Asian older people in the community are the:
• Guru Nanak Day Centre in Gravesend
• Milan Day Centre in Dartford
• Sahayak project
• Advocacy Network
• KCA (UK) (Kent Council for Addiction UK)
• Grand project.
• Presentation Housing (see above)
• Denton Family Centre
• North West Kent Racial Equality Council
• Guru Nanak Darbar Gurdwara in Gravesend and
• Gurdwara in Dartford.
The Sahayak project is based in Gravesend and works with individuals from minority ethnic groups. It provides a telephone help line and befriending service for those experiencing mental distress and their carers.

The Grand project is Gravesham’s Healthy Living Centre that aims to raise health awareness among ‘at risk’ groups including the elderly and ethnic minority groups. The project has Asian staff members who are responsible for developing programmes to educate the community about a wide range of health matters.

KCA is a Gravesend based voluntary organisation that aims to help people with concerns about alcohol or drug use. This organisation also has a designated worker to work specifically with members of the ethnic minority community.

The most popular and ‘acceptable’ statutory service is day care for frail elders from the Asian community. Whilst this is culturally appropriate it is not specifically developed to support older people with dementia. Another important issue is the employment of Asian workers whose specific remit is to work with Asian service users and/or carers. They tend to speak the same language as the older Asian users, recognise religious festivals and cultural mores and can relate to the users experiences.

**Key Points:**

- There is a network of voluntary and statutory groups in the local area that provide services to people from minority ethnic groups
- All service providers welcomed the initiative and were keen to engage in discussions to improve access to dementia services by the Asian community
- The largest numbers of Asian elders use the statutory day care services provided for physically frail elders, not dementia services
- Having at least one dedicated Asian worker whose specific remit is to work with the Asian community is an important aspect of service provision

**Mapping the Mental Health Needs of the Asian Community**

In this section findings from interviews with GPs, service providers and carers are presented.

**Data from General Practitioners**

The following section summarises the responses given by GPs illustrated by quotes. The data presented in Figures 4-7 has been analysed by looking for key themes that emerged from these interviews. The profile of the GPs is described in Section 3.

**Dementia awareness and diagnosis**

All GPs agreed that most Asians in the local community are not aware of what dementia is and that they accept many of the early changes associated with dementia as a ‘normal’ part of the ageing process. Most GPs felt that there is a greater tendency among the Asian population to associate memory problems with ageing than is the case for the indigenous population (Figure 4). There was also a tendency for Asians to present at later stages of the illness (Figure 5).

**Figure 4**

*Many older people consider memory problems as a normal part of the ageing process. Is this more or less often among Asians?*

**Figure 5**

*Do Asians present at later stages of the illness?*
In addition to answering specific questions, GPs were invited to make additional comments and the quotes below illustrate some of the challenges that GPs face in trying to diagnose dementia.

‘Many Asians don’t want a firm diagnosis’

‘Asians don’t readily accept care workers’

‘So long as they are coping, they don’t want any other services’

‘There is a stigma around the problems and often they are embarrassed to talk about the symptoms’

‘For Asians, illnesses have to be physical - they somatise everything and diagnosis is very difficult’

‘We need to raise awareness among the community about dementia and memory problems. Asians don’t distinguish between dementia and mental illness and don’t talk about it because of the stigma.’

Treatment, care and services
To establish what was happening to the patients once they had approached their doctor, GPs were asked to comment on the course of action/treatment they took for these patients.

Around 83% of GPs said they would refer onto the psycho-geriatricians (Figure 6) but could not necessarily give the name of whom they would refer to. Interestingly, data from the health professionals and carers surveys (presented later on in this report, see Figures 8 and 17) does not endorse this finding.

Only one GP referred patients to ADSS regularly and another said that all the GPs at the practice referred on to social services who put in a package of care through care management. Two GPs mentioned prescribing drugs for their patients; however one of these was referring to a daily dose of soluble aspirin rather than to anti-cholinesterase drugs.

One of the questions asked: ‘What services are available locally for patients with dementia?’ This was included to gauge the knowledge of GPs about local services for dementia patients and their carers. The two quotes below illustrate the contrasting degree of knowledge about dementia services.

‘ADSS, Crossroads, Carer’s support groups. Generally the care manager will do the referring on to services.’

‘The only service is at Stone House - the psycho-geriatricians. Patients over 60 with memory problems are referred to a neurologist for a scan. There are no other services.’

Service development and training
In response to a question about additional services for Asian patients with dementia and their carers (What additional services would you like to see in place to help with the care of Asians elders with dementia a) for patients, b) for carers?), four GPs said they would like to see day care services for their patients; other answers included:

• respite beds in Nursing homes (2)
• EMI beds (1)
• more professional carers for homecare services (1)
• overnight support at home (2)
• an Asian helpline (1) and
• simpler referral systems (1)

Two quotes summarise most of the responses:

‘Yes we need much more in the way of respite for carers. More support at home for the carers. Need good EMI residential care. The psycho-geriatricians avoid putting a label of dementia because there aren’t enough services to offer them; there is a severe shortage of EMI beds’

‘An EMI home for Asians would be good, we have around 17,000 Asians in Gravesend.'
We have to look at the cost of delaying the progression of dementia over other things such as heart disease and diabetes, which are very high among the Asian population, and there is very little support available for them. Also these and other diseases affect younger people and it is important to weigh up who you are going to prioritise treating, as there is only a limited pot of money available. Doctors have to make these kinds of decisions all the time and I wish we didn’t have to.’

In terms of specific gaps in dementia care, comments on professional deficits included:

‘There are not enough interpreters or enough CPNs. We need Asian CPNs who speak the language.’

GPs were asked their opinion as to why there is such a poor uptake of ADSS and other dementia services by the Asian community (Figure 7). All GPs, including those who the researcher spoke to informally at meetings, agreed that the main issues for the community were the lack of knowledge about the condition and about the availability of services, cultural differences, language difficulties and the very high degree of stigma associated with dementia and other mental health problems.

All GPs also felt that there is a need for further training among health and social services professionals around dementia and cultural awareness.

‘We all need more training in specialised fields.’

Key Points:

■ GPs recognised that most Asians don’t know what dementia is and that they accept the early symptoms of the disease as a normal part of the ageing process

■ Most GPs interviewed were not well informed about local services available for patients with dementia and relied on Social Services care managers to refer patients on to other services

■ The GPs understood the community well and felt frustrated by the lack of cooperation from Asian patients when trying to diagnose dementia and other mental health problems

■ Services GPs thought should be developed included: respite care, more EMI beds, home based overnight support for carers, simpler referral systems, more CPNs and interpreters

■ GPs recognised that the main barriers to the uptake of services by the Asian community were: a lack of knowledge about services, cultural differences, language difficulties and a very high degree of stigma experienced by Asians with mental health problems.

■ All GPs interviewed agreed that they themselves and other health and social services professionals would find further training around dementia and cultural awareness helpful.
Data from Service Providers

The profile of the service providers is described in Section 3. This section draws together some of the key themes that emerged from the face to face interviews and self-completed questionnaires.

Service usage by older Asians with dementia

To gain information about the services already accessed by Asians and how to improve access to other services, providers were asked the following two questions:

‘If Asian patients are not coming forward for help, why not?’

‘What can be done to change the situation?’

Figures 8 and 9 show the responses obtained and it is interesting to note that in Figure 8, five respondents (16%) said that many Asians access their services. All five of these were Asian workers who were either specifically recruited to work with ethnic minorities or, were working in a service specifically for Black and ethnic minorities. Figure 8 also shows that a large number of people in the survey felt that the main barriers to Asians accessing services were around issues of confidentiality, stigma and finances. Interestingly, all those who gave these comments were either Asian or from another BME community. Several people said that their service was dependent on referrals from other sources; those who commented specifically on GPs not referring on to services included the psycho-geriatricians and other hospital-based staff. This finding clearly conflicts with the response of GPs in Figure 6.

There was a very genuine concern among some social services staff about the quality of the service they were providing to members of the Asian community. They welcomed the research project in the hope that it would lead to better services for their clients.

‘I don’t feel we provide a good service to the community because we cannot communicate with them. We are willing to learn the language.’

In contrast to the above responses, the views held by some other professionals were rather disconcerting as they reflected the very myths that have been challenged over the years and the Eurocentric nature of some of the service provision in the area.

‘I’ve always felt that Asians are looking after their own and as such I wouldn’t expect more to be accessing our service.’

Other questions aimed to gain information about the methods used by service providers to attract Asian clients to their services. The results showed that the most common method employed was to use leaflets with ten respondents (31%) indicating that they have leaflets about their service. Nine respondents (28%) said that they did not have any specific method of promoting their service and they relied on referrals from GPs and other health professionals. Seven respondents (22%) said that they had information in Asian languages and seven of the organisations had employed at least one Asian worker who had a responsibility for outreach work within the community.
Dementia awareness and help seeking

Almost half of those taking part in the survey said that there was a need to raise awareness and do outreach work in the community and this included raising awareness among GPs. The comments below from a health services professional covered many of the points raised.

‘Asian patients don’t come forward. There are problems with recognition of the disorder. GPs don’t have much time and Asian elders don’t get care throughout e.g. BP management, diabetes etc. GPs don’t refer on. We need to improve patient/population knowledge, make GPs more aware of care pathways, make our services more user friendly and recruit more Asian staff. A GP register for dementia patients should be kept and the ethnicity of patients on the register monitored. GPs should also do the over 75s health check.’

A number of the questions were intended to uncover the issues that Asians with dementia and their carers raise with service providers and whether these differ in any way from the issues raised by their counterparts in the indigenous population.

The questions were as follows:

- What issues/triggers do clients bring to your attention?
- What issues/triggers do Asians bring to your attention if they are not familiar with ‘dementia’?
- Are the issues that Asians bring to your attention different from those of other groups?

Figure 10 shows that 11 respondents (34%) mentioned the usual symptoms associated with dementia such as forgetfulness, wandering and anti-social behaviour and another seven (22%) mentioned carer’s issues where the role of the carers had changed and become increasingly difficult.

Figure 11 shows that 41% of those who answered the question felt that the issues Asian clients brought to their attention were different to those raised by other groups.

‘They never use the word ‘dementia’. They will often say things like ‘because of old age she/he is going mad’. They show much concern for what other people think and try to hide it. Often they will send the person to another relative, particularly female relations, i.e. daughters.’

‘They complain of being depressed and not achieving the housework etc. but this is loss of skills. Asians come forward later on in the illness. None of them are on medication for dementia because they are at advanced stages or have vascular dementia.’

‘Sometimes I hear the young daughters-in-law saying things like their relative has become child-like and also they often describe them as having gone insane.’

However, 17 people (53%) said that they did not know or could not comment because of their lack of experience with Asian clients.

Barriers to uptake and service development

The interviewees were asked questions to address the reasons behind the low uptake of ADSS and other existing mental health services and also to collect their views on the kind of services needed for the Asian community.
The next two figures, 12 and 13, show the responses obtained.

**Reasons for the poor uptake of ADSS and other mental health services by the Asian community.**

![Bar chart showing reasons for poor uptake of services.](image)

Key:
1. Ignorance about services
2. Cultural differences
3. Language problems
4. Stigma
5. Other

**Figure 12**

It is clear from Figure 12 that the main reasons for the low uptake of services were thought to be ignorance about services, cultural differences, language problems and stigma.

Several other reasons included the following:
- the lack of cooperation by Asian patients
- transport issues
- the lack of ethnic minority staff in some services and
- service providers not marketing their services to the Asian population.

Figure 13 shows that 77% of the interviewees felt that new dementia services for Asians could be integrated into existing services. However, nearly half of these made additional comments such as:

‘Ideally’

‘Maybe we will need separate services for the current generation of Asian elders.’

‘Yes, because of budgetary reasons. Specialist schemes only need to be in place for the next 10 years.’

‘Yes, 24 hr care can be integrated. It would not be realistic to set up separate services, as they have to be very local. Day care would be better as a separate service.’

Only four people said ‘no’ and two of these were clearly referring to the current generation of Asian elders as they made comments such as ‘No, not yet.’

A question was also included about the needs of Asian carers:

‘Is there a need for specific services for Asian carers?’

75% of respondents answered ‘yes’, 9% said ‘probably’ and 13% said ‘no’. Several respondents stressed the particular need for services in the Dartford area since there were already some services available in Gravesend.

‘Perhaps Dartford could do with a group like the Sahayak carer’s group in Gravesend. Informal support between carers would be useful.’

They identified the main services accessed by Asian elders as the Asian day centres in Dartford and Gravesend with very few Asian elders or carers accessing specialist dementia care. These are more acceptable.

**Key Points:**

- Service providers consider the triggers to help seeking amongst older Asians to be: forgetfulness, wandering and anti-social behaviour as well as carers’ dealing with more challenging behaviour
- The main services accessed by Asian elders were the social services Asian day centres in Dartford and Gravesend with very few Asian elders or carers accessing specialist dementia services
- Although the day services are more ‘acceptable’ because they are not mental health services, they are not appropriately resourced for managing dementia
Services that did not have any Asian workers were unlikely to be accessed by Asian elders or their carers. In contrast, services that had at least one Asian staff member, with a specific remit to work with the Asian community, were readily accessed.

The main reasons for the poor uptake of dementia services by Asians were: a lack of knowledge about the condition and about services, GPs not referring on to services, communication problems, stigma and fears about breach of confidentiality.

Many service providers are concerned about the lack of appropriate provision for Asian elders with dementia.

Most service providers felt that new dementia services for Asians should be integrated into existing services. However, they also recognised that the current generation of Asians may need separate services.

Data from Carers

Data from the seven interviews with carers is presented below. Details about the carers are described in Section 3.

Triggers to help seeking and services

All the carers said that the two most significant changes they had noticed in the person they were caring for were the loss of independence and an increasing level of frustration due to their relative’s declining ability. The symptoms that some carers were struggling to understand and cope with included increased aggression and paranoia.

Questions around the organisation of care in the household (Figure 14) revealed that five of the seven people interviewed said that their relative needed 24-hour supervision. Three carers had managed to get a place for their relative at one of the Social Services Asian day centres and two others were in long-term care.

It is interesting that where the main carers were males, both the cared for older persons were in long-term care. The other five dementia patients were being looked after by female relatives (daughters or wives) rather than the male relatives (sons or husbands) even where these existed.

Figure 15 focuses on the help that carers were getting and the help that they said they would like. 71% (five carers) had experience of their relative being in hospital because of the dementia, either at the time of the interview or over recent months.

The Asian day care service was perceived to be the most helpful type of service by the three carers who accessed it and it was requested by all five carers.
One carer was not getting any help at all and, because of the language difficulties, the only two service providers she had contacted were those voluntary organisations that had Punjabi-speaking staff. This carer contacted the project researcher after hearing one of the dementia awareness broadcasts on the local Asian radio station (Khalsa radio).

All of the carers felt that in the future dementia services for Asians should be provided within mainstream care. Access to Asian staff is required for at least the current generation of older people.

Accessing services
Figure 17 shows that all the carers had experienced difficulties in trying to access services for their relative. Not surprisingly, all the carers felt that language was a particular difficulty and made communication very difficult. Some of the ‘other’ difficulties experienced by carers included: bureaucracy within the system, a lack of liaison between professionals and GPs being unsupportive, dismissing the early symptoms as old age and not referring on to other services.

‘In the beginning the GP just kept saying she is getting old. We had to put a lot of pressure on the doctor and it took a couple of months after the wandering incident before we began to get anywhere.’

Five of the seven carers said that they would use services more if they could cater for the language and cultural needs of their relative. The services that were perceived to be least useful were carers support groups and befriending services.
Interestingly, all the carers said, ‘yes’ to using residential homes, even though at times during the interview they indicated that the notion of putting their parent in a home was completely unthinkable. This may have been because by the end of the interviews the carers had a better understanding of the likely decline of dementia patients and may have begun to recognise that managing their relative at home would become increasingly difficult over time.

**Information giving**
Few carers had been given accessible information, either about how to manage or to deal with their relative’s dementia. In terms of information about services, one carer had not had any information at all, four had been given information about the Asian day centre and only one carer knew of ADSS. Six of the seven carers said that they had not been given any information about support services for themselves. One carer had been given information about support groups by hospital staff on Thames Ward. Few carers knew they were entitled to any additional, or carer related, welfare benefits.

**Concerns about quality of life**
All carers had concerns about the inactivity of their relative with dementia. Most said they spent many hours each day engaged in passive activities such as just ‘sitting around with the television or radio on’.

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**Key Points:**

- The majority of carers were providing 24 hour supervision for their relative without any respite from their caring role.
- The most significant triggers in prompting help seeking were the loss of independence of the person with dementia and the carers level of frustration around declining abilities.
- ‘Increased levels of aggression’ and ‘paranoia’ were noted as the two most challenging symptoms of dementia to understand and cope with.
- Some of the cared for relatives either attended an Asian day centre or were in long-term care; day care is regarded as very helpful and it is the one service carers want greater access to.
- The main barriers to service usage are: linguistic and cultural issues, bureaucracy and GPs failing to refer users on to specialist care.
- All the carers had wished they had been given more information about how the illness would affect their relative.
- Carers felt that in the future dementia services for Asians should be provided within mainstream care; access to Asian staff is required for at least the current generation of older people.
- Carers support groups and befriending services were not perceived as useful.
- All carers said that they would only consider residential care for their relative if it became impossible to manage at home.
Data from Workshops and Focus Groups

This section presents data from three types of sessions held within the community:

• Information workshops to community groups
• Focus groups and
• Raising dementia awareness sessions

The workshops proved to be a very significant aspect of the project. They provided a vehicle for:

• promoting the project’s aims
• enhancing understanding of dementia
• informing members of the Asian community about services and service availability
• exploring the specific support and service related needs of Asian elders with dementia and their carers and
• recruiting interview respondents

As the project was rolled out and community members became more familiar with the researcher, workshop attendance increased and participants became more willing and confident about engaging in discussion about dementia. The popularity of the workshops spread as more and more people took advantage of the educational opportunities offered. Often one workshop would lead to a request for another, including two that were run for the Chinese community. As the key aim of this project is to scope the dementia related needs of the Asian community, most material from these workshops is not included below. However, it is worth noting that the workshop attendees from the Chinese community were quick to grasp the relevance of dementia issues and the need to develop appropriate dementia services for their older members and carers (Elliot et al, 1996; Joseph Rowntree Foundation, 2000).

Workshops to Community Groups

Three of the workshops were delivered at the two local Asian day centres, the Milan Day Centre in Dartford and the Guru Nanak Day Centre in Gravesend. Each of these was attended by a group of elderly clients of the day centres and two members of staff.

Due to the attention span of some of the service users, the focus of these sessions was to raise dementia awareness among the groups, rather than to engage the participants in discussion about stigma and services. Nevertheless, some of the comments made by service users during the sessions were indicative of their discontent. For example, after the showing of the video ‘Dementia Ki Hai’ at one of the workshops, an elderly lady signalled the researcher over to the chair next to her and commented:

‘There are several ladies among us who have this illness and they should have somewhere else to go. It is not right that she (pointing to the lady in the chair next to her) is here. She just keeps asking the same thing over and over again. She doesn’t know where she is, what she’s doing or where she is going.’

The researcher informed the group about services in other parts of the country for Asians with dementia and questioned why there weren’t any similar dementia services in the Study Area. One elderly woman responded:

‘I know that in other areas there are lots of services for Asians, but in this area the council does not want to spend the money for services for us. We don’t even get a free bus pass in this area whereas in other areas they do.’

A cultural viewpoint expressed by another workshop participant helped to explain a possible contributing factor to the lack of development of specific dementia services for Asians in this area:

‘We are slow to ask for help because we are brought up that way. We are taught throughout our life that while we are young our parents and grandparents look after us. Then when they are old, it’s our turn and responsibility to look after them. So now we expect our children to take care of us.’

Many of the elderly women showed empathy with the carers in the ‘Dementia Ki Hai’ video coping with dementia symptoms in their partner. This included both verbal agreement and non-verbal gestures such as nodding and tutting to show their sympathy for the couple. Several of the women repeatedly said short words of prayer when they understood how the illness could affect elderly people, especially when talking about the symptoms in the later stages of the illness such as not recognising close family members. These words of prayers were
said several times during both the dementia presentation and the video.

The session with the elderly men’s group at the day centre also revealed interesting data. Some of the participants were keen to discuss their concerns about their own memory loss and that of another member of their group who was not present at the time.

‘I think I’ve got this illness, whatever you tell me today, I won’t remember it tomorrow. Sometimes when I’m out shopping I can’t remember what I need to buy and often when I’m doing something, I find I’ve forgotten what I had set out to do.’

‘There is only one other person (Mr. X) who attends this centre and has dementia, but he’s not here today, so maybe I can just take some of your information and pass it on to him.’

The fact that older Asians - and sometimes Asian staff - are prepared to share personal details about the medical symptoms and conditions of others in a public setting does raise issues of boundaries and respect for confidentiality. It also adds weight to these comments:

‘Sometimes if you fight to get help or a service, it can have a very negative effect. For example, I felt that my rights were taken away when I tried to access the day centre. Confidentiality is breached all the time and everyone ends up knowing your business, especially if you have complained about someone or about a service.’

‘It’s often the service users of the day centre who talk to each other and then gossip about what they have found out about afterwards.’

Raising Dementia Awareness
Links were made with community leaders to facilitate an evening session of raising dementia awareness at the local Gurdwara in Gravesend. A presentation to the congregation was followed by a ‘surgery’ session when the researcher and another staff member from ADSS were present to talk to individuals who had concerns either about their own memory or that of another elderly person. Information was made available on a wide range of carer and service user issues in relation to Alzheimer’s and dementia. This event took place at a time when the Gurdwara had its own radio channel broadcasting to the local community and therefore the messages about dementia reached a much wider audience than was present in the congregation.

Twelve people came forward for information after the presentation and eight of these gave their names and addresses so that they could be invited to the next workshop in the community. Three others took away information after discussing their concerns with the ADSS staff members and two other people contacted the researcher by telephone after the event. Interestingly, one of these carers commented that she had heard about the research project on more than one occasion previously and had been contemplating contacting the researcher. When she did finally make contact it was because of the dementia awareness message broadcast from the Gurdwara.

‘I felt Baba was talking directly to me. He had listened to my prayers and this was his answer to me.’

Focus Groups
Four focus groups were held over the duration of the project with a total of 48 male and 32 female participants. They were all Asians from the local area and included lay members of the community, professionals, volunteers and a large number of retired people. There was very little basic knowledge of what dementia is among the groups, indicated by participants asking questions such as: ‘Is it contagious?’ Therefore each session also had a significant element of raising awareness. At the end of a presentation on dementia and a showing of the video, the groups were broken down into smaller groups and asked to discuss the following three questions:

1. Is dementia the result of old age or disease?
2. Why the stigma?
3. What services/help would you like to see in place?

The responses to the first question, ‘Is dementia the result of old age or disease?’ showed a large variation in the views held.
Some examples of the answers given are listed below:

‘If the symptoms occur at a young age then we’d think it was disease, but in old age it is different, we should observe the progression of the symptoms. When a woman has a hysterectomy, some depression occurs; when the menopause takes place, it also affects us mentally.’

‘It is a deformation of the mind and it is purely due to old age.’

‘Dementia is due to old age.’

‘In my opinion it is a disease of old age.’

‘Old age is not a disease but a blessing if we approach it properly.’

It became clear from the responses of some individuals (nearly always men) that they found it difficult to accept that dementia is anything other than a normal consequence of the ageing process. Indeed the responses of these individuals to the next question, ‘Why the stigma?’ also revealed some of the reasons why Asians do not want to accept that anything is wrong.

‘Because of self-pride, ignorance, and you are socially considered downtrodden and outcast if you have to ask for help. Self-pride covers a wide range of our cultural background. We always think of what other people will think of us rather than our own difficulties.’

‘Social reasons. Resignation to the belief that you should appear reserved and hide the problems.’

‘Among Asians it is considered that the family should look after them when a person has got a problem. People generally try to shield their problem until it becomes acute.’

‘In Punjab people want to cover up the disease. They want to look fit to other people; it’s some sort of ego. They think that if they disclose the disease they will be looked down upon by other people.’

‘Because it’s an illness of old age due to worries and loneliness’

‘Because of lack of information’

‘Our society looks unfavourably on people who have to ask for help and this has originated from how we were brought up back in India. We are embarrassed to ask for help - what will people think?’

‘Our culture is such that we care for our elders at home. People will talk about not caring for them in old age.’

‘Our culture says that we must look after our older relatives. I would feel let down by my family if they didn’t look after me in my old age.’

‘Nobody wants to admit that they might have someone who is ‘pagal’ in their family so we just manage as well as we can within the family but it can be very hard on the main carer.’

The last question focused on services that the participants would like to see in place for their community members with dementia and their carers. They were asked to consider services that they would use themselves should the need arise. Most participants said that they would like to see a specific day centre and others commented on the community’s continuing need for information to ensure that carers are encouraged to ask for help when it’s needed.

‘We would like to use a day centre for our people with dementia. Existing residential homes could be made accessible to us by introducing BME nurses and other staff to overcome language barriers and cultural things.’

‘The community needs more information about dementia and also about what help is available for carers. We also need information on what financial help is available and how to access things like meals on wheels, social services etc. We also need to have the contact number of a person to whom we can address our concerns.’

Some of the comments from women in the focus groups pointed to a fundamental difference in the attitudes and expectations between the two genders:
‘We have to look after ourselves and get help, because our men will just let us carry on working until we get so ill mentally and physically that we can’t anymore.’

‘We don’t know anything about these illnesses and therefore don’t know when we should or shouldn’t ask for help. We only ask for help when we can’t manage any more.’

Financial concern, particularly about paying charges for services, was another common issue. Some individuals were very reluctant to pay charges for social care services arguing that they had paid their taxes and were entitled to free services. They took the view that paying for services is effectively paying twice.

‘I would like to see a free day centre specifically for patients with dementia; if it’s not free our people won’t use it.’

‘I think she needs services; I’ve tried to get them (referring to homecare services) to come in for her, but they want me to pay for that. Why should I pay for that – I won’t.’

Other comments about services from the focus groups included:
‘We need to be able to use a residential home for our elderly.’

‘We need respite homes to give the carers and family a break.’

In contrast, others held very different views:
‘Our culture says that we must look after our older relatives. I would feel let down by my family if they didn’t look after me in my old age.’

Key Points:

■ The workshops and dementia awareness raising sessions proved to be a very significant aspect of the project and were very popular with a wide range of participants

■ Empathy was shown for carers struggling with supporting a relative with dementia in a video, indicating a greater level of awareness of the issues than is openly acknowledged

■ There was very little basic knowledge about dementia among workshop participants

■ Some older people felt able to discuss concerns about their own memory problems and those of others in a focus group setting

■ The fact that older Asians are prepared to share personal details about the medical symptoms of others in a public setting raises concerns about respect for confidentiality

■ There was evidence of a very high degree of stigma associated with dementia and other mental health problems within the community. This contributed to a reluctance to acknowledge the symptoms of the illness and get help

■ The cultural upbringing of Asians acts as a barrier to community members readily accessing help. Specific barriers include: service charges, a need to hide problems, pride, familial duty, concern about what ‘others’ think and the perception that using services is a sign of failure

■ Other factors that contribute to the lack of uptake of services are: lack of knowledge of dementia, lack of knowledge of help available, communication difficulties and not knowing whom to contact.
Data from telephone survey of Residential and Nursing Homes

Of the 21 homes contacted, 19 had no Asian residents. Furthermore 17 had not had any enquiries about placing an older Asian over the last year. Two homes had two Asian clients each. Both of the clients in one of the homes could speak English; the opposite was true for the second home. This home had one Asian part-time staff member and some of the other staff members had made efforts to learn a few words of Punjabi in order to communicate with the Asian residents. In total, four of the homes employed Asian staff.

Two homes had received enquiries from Asians seeking a placement over the previous year but neither of these had resulted in a place being taken up. In each case the reason given for the place not being taken up was an inability to meet the linguistic and dietary needs of the clients. Interestingly, the owner of a small, privately run home, who belonged to a minority ethnic group herself, commented:

’No, we don’t have any Asians in our service, I think they keep them at home and look after them themselves. That’s what they do back home in my country.’

Key Points:

■ Of the total number of 21 care homes contacted, 19 had no Asian residents and 17 had not had any placement enquiries over the last year

■ The other two homes had two Asian residents apiece

■ The home where the two residents only spoke Punjabi employed an Asian staff member; some of the English staff had also made efforts to learn some Punjabi

■ In total four of the care homes employed Asian staff

■ There is evidence that placements do not proceed as a consequence of the care homes not being able to accommodate the linguistic and dietary needs of older Asians

Discussion

This section will draw together key findings of the research and discuss them under a number of themed headings.

Understanding of Dementia

One of the most striking findings of this project was the lack of knowledge and understanding of dementia among members of the Asian community. Most Asian participants - including several professionals - were not familiar with the terms ‘Alzheimer’s disease’ or ‘dementia.’ They did not conceptualise the illness as an organic disease that is associated with, rather than a consequence of, old age as it is understood to be in the West (Innes, 2001). Asian languages, including Punjabi, do not have an equivalent word for dementia. This is a consistent finding of research in the field of ethnicity and dementia; a number have specifically highlighted the lack of understanding dementia sufferers and Asian families have of the illness (Patel et al, 1998; Brownfoot and Associates, 1998).

This conceptual frame has implications for how Asian families understand dementia related needs. The project identified the almost universal negative perception of older Asians with dementia as ‘behaving in a child-like way’ and ‘losing their senses and ability to understand’. In its early stages, dementia is often regarded as a ‘normal’ part of the ageing process and as not amenable to treatment or other intervention. This perception, coupled with the lack of knowledge about treatment and services, acts as a powerful barrier to both users and carers seeking help or advice.

A lack of understanding of dementia can negatively affect the quality of care provided by families (Katbamna et al, 1997). Indeed, there was a tendency among some carers to blame the relative for his/her symptoms:

’I don’t know why she does and says the things she does, I don’t know why God is punishing me or how long it’s going to go on .... She isn’t my mum anymore and I wish God would just take her away from me now.’
Cultural Beliefs
A powerful set of findings relate to the role played by cultural beliefs. That there is reluctance among Asians to ask for help is not surprising given their cultural expectations (Seabrooke & Milne, 2003). Asian children are brought up in an environment that places great emphasis on the importance of being self-sufficient and standing on ‘one’s own feet’ throughout life. An embedded desire to portray an image of well-being to those outside the immediate family is also strong as is the need to hide the existence of mental health problems. Research exploring the latter issue identifies damage to marriage prospects of children in the family as an underpinning cause (Patel, 2000; Wellard, 1999). The related stigma associated with acknowledging mental ill health is particularly negative for older people with dementia and contributes to the sense of family duty to care, whatever the impact on the carer as well as to the noted resistance to seeking help from services. A number of comments made during the fieldwork support these findings, for example when referring to an Asian lady in her nineties one GP said:

‘She needs more help and more care but the family don’t want to know as they are concerned about what people will think.’

Confidentiality is a particular issue for Asians, especially in a community as close as this one; most community members would acknowledge that, culturally, Asian people tend to talk about each other’s business.

Diagnosis of Dementia
Recognising the symptoms of dementia by the individual or their relatives is widely noted as a prerequisite for diagnosing and treating dementia in its early stages (Milne et al, 2000). Early diagnosis is linked to health and social care support for users and carers and offers a significant opportunity to plan ahead and put one’s affairs in order (Milne and Wilkinson, 2002). One of the specific aims of the NSF for Older People is to facilitate early diagnosis as it, ‘... gives access to treatment, allows planning for future care, and helps individuals and their families come to terms with the prognosis’ (Department of Health, 2001). The NSF goes on to state that the early detection of dementia is particularly important for those with a vascular dementia as two of the known risk factors - hypertension and diabetes - are treatable. Treatment can improve cognition and delay or terminate recurrent cerebral infarctions (Amar & Wilcock, 1996). That these are particular vulnerabilities for older Asians makes the need for early diagnosis and treatment imperative.

The fact that many Asians ignore, or fail to acknowledge, the early symptoms of dementia, results in missed opportunities. The finding that most Asians with dementia only come to the attention of services at an advanced stage when the potential to offer preventive treatment is very limited, confirms this. A second consequence relates to family care; carers tend to seek help at a later stage in the dementia care trajectory which creates higher levels of stress and reduces quality of life for both carer and cared for (Chryssanthopoulou & Milne, in press).

The study identified a number of challenges facing GPs who tend to be the first port of call for Asians with concerns about dementia. The lack of willingness amongst many Asian patients and their families to acknowledge dementia symptoms, coupled with the pressures of the average GP workload, undermines the facilitation of early diagnosis. That many GPs do not regard dementia care as a priority is also a disincentive:

‘Asians accept minor degrees of memory impairment as a normal part of old age. I am much more concerned about things such as diabetes, hypertension and stroke for which I see lots more patients. Doctors generally will be more concerned with diseases that are seen in younger patients for which they can save lives.’

Diagnosing dementia can of course be problematic in people from ethnic minorities, particularly if service users do not speak the same language as the assessing practitioner. Moreover, the standard ‘tests’ used for detecting dementia may not be culturally appropriate and can lead to inaccuracies in diagnosis as well as a reluctance to ask for help due to fear of stigma and of receiving a label of ‘madness’.

Overall then, despite the emphasis placed on early diagnosis by research and policy this study suggests that older Asians do not seek out, or routinely receive, early diagnosis of dementia or preventive intervention. The urgency to address...
this deficit is fuelled by the fact that two of the causes of vascular dementia are treatable when presented at an early stage.

**Access to Services**

Service providers in the area, particularly those working in the field of dementia, are keen to see an initiative designed to improve access to, and the quality of, dementia related services for people from the Asian community. Many practitioners are already aware that the number of Asians using their service does not reflect the actual percentage of Asians with dementia in the local population and that more needs to be done to improve accessibility to services. The need to break down the barriers between the Asian community and service commissioners and providers, has been identified as a priority, as has the development of specialist care specifically for the current generation of older Asians with dementia.

The lack of knowledge among minority ethnic groups is not the only barrier to accessing services; a lack of knowledge among health care workers and other professionals, about the lifestyles, health, religious and cultural needs of minority communities can also present as a disincentive to the uptake of services. Language and communication difficulties, transport issues, charges for services, the complexity of the care system, lack of accessible information and limited GP referral on to secondary health care or specialist support services are also noted.

Another significant barrier relates to an issue noted above; it concerns breach of confidentiality by service users and workers. This finding suggests a rather too permeable relationship between services and the wider community and that information shared in a service context may be discussed outside of that environment. Staff may not adhere carefully enough to a professional code of conduct which ensures the protection of users and carers (Milne, 2002). One carer noted: ‘everyone knows everything as soon as you tell one staff member.’

A number of workshop participants had experienced specific breach of confidentiality in the day centres in NW Kent where large numbers of elderly Asians and staff members are present. Considering the stigma related to dementia and the fact that families go to great lengths to keep a diagnosis of mental illness hidden, this may have serious consequences for older Asians with dementia and their families. It also raises the importance of training.

Many service providers acknowledged that local mainstream provision for dementia service users was neither easy to access nor appropriate for people from the Asian community. They generally attributed the low uptake of their services to a mismatch between the linguistic, cultural and religious needs of the community and their provision. In contrast, the project has also identified the existence of attitudes, among a minority of service providers, that are unhelpful to the agenda of encouraging people from ethnic minorities to take up services. These attitudes were reflected by comments such as:

‘Anyone can use this service, there are no restrictions to any particular groups’

‘Everyone is equally welcome here.’

Such attitude assumes that the needs of people are the same, regardless of their ethnicity and experiences. It also gives rise to the premise that the service is ‘fair’ as everyone is treated the same. However, providing the same service for everyone, when in fact the needs are different, cannot be equated to providing an equitable service since the outcomes of using the service may be very different for service users from different community groups (Blakemore and Boneham, 1994). Furthermore this approach assumes that everyone will readily take up the service provided; if they do not, it is seen only as a cultural issue.

In terms of the services that are currently used by Asian elders and carers, it is clear that services run for members of the Asian community and, to a lesser extent those services that employ Asian staff, are accessed more readily and are more appropriate. Asian day care services are particularly highly regarded as are the Sahayak project and the Advocacy Network. The meeting of linguistic and cultural needs is important; among other factors, this includes attention to religious issues, hair, diet and gender and age specific practices. The fact that day services are not specifically designed or staffed for the care of people with dementia raises the issue of quality
of care and highlights the greater acceptability of using ‘generic’ Asian services or medical services rather than services that have the label of ‘mental health’, ‘psychiatric’ or ‘social care’. For example, the facility for dementia patients at Stone House Hospital is regarded as relatively acceptable because it is a ‘medical’ and not just a mental health unit.

Support Needs of Carers
Before going on to discuss the project findings with regard to the support needs of Asian carers it is important to acknowledge that many difficulties are encountered by all carers of people with dementia (Milne et al, 2001). Published studies have suggested that in many respects the experiences and needs of minority ethnic carers mirror those of carers in the white community (Atkins and Rollings 1996). However, evidence also suggests that there are some differences in their experiences. These are associated with religion, culture, socio-economic status and being a minority within a majority population. Furthermore, the experiences and needs of ethnic minority carers are shaped by the level of formal and informal support (Katbamna et al, 1997) including reluctance amongst Asian carers to make use of support services.

Asians who are caring for a dependent family member do not perceive themselves as ‘carers’ but as a daughter, daughter-in-law, or spouse who is simply ‘doing their duty’. However, the cost of fulfilling the care responsibilities can be immense for the main carer and sometimes for other family members as well. Many either give up work or cut down to part-time employment to accommodate the demands of caring (Milne and Williams, 2003). This was also apparent in the Study Area and even though the carers were under enormous stress, they were unwilling to relinquish their caring role completely unless it was to another trusted relative. Whilst some carers found the thought of transferring their relative to a ‘residential home’ objectionable, other members of the community did acknowledge that the advanced symptoms of dementia may require this type of support. The long-term facility for dementia patients at Stone House Hospital was acceptable and sometimes welcomed by carers as it not only provided care but also fulfilled the medical needs of the older person. It is noted that hospital services are free in contrast to the high cost of residential and nursing care. Furthermore using hospital services elicits sympathetic responses from other community members as opposed to the reprehensible attitudes to ‘putting him/her in a home.’

Many respondents commented on the need for carers to have breaks from their caring role. The finding that carers wanted respite from their caring role and had not been offered any was interesting. The fact that respite care is available in NW Kent suggests two things: that assumptions about Asian families ‘looking after their own’ continues to influence service providers and that Asian carers remain reluctant to ask for help even when it is so evidently needed. So far service planners have tended to be largely reactive to the needs of Asian carers; they need to become more proactive and tackle the underlying issues of diversity and equal opportunities.

Inter-generational Conflict
Whilst not directly addressed in the fieldwork to any significant extent the role of inter-generational conflict cannot be underestimated in considering the role of the family in meeting the needs of older Asians with dementia.

A number of Asian professionals identified the increasing level of conflict between the expectations of the older generation Asians and the aspirations of their younger second generation offspring. Having grown up in a Western environment, the younger generation have engaged with the indigenous population far more than their parents; they tend to have different priorities, beliefs and values, which creates a cultural conflict between the ‘traditional’ and the ‘Western’. This clash of cultures has undermined family bonds, assumptions about inter-generational reciprocity and traditional support structures. The marriage of younger Asians to partners from other areas of Great Britain is of particular significance given the nature and patterns of family care in Asian communities referred to earlier in this report. One Asian professional commented:

‘Asian elders come to me often and say, the family unit has broken up, the children don’t care... they don’t want to live in the family unit or look after their parents any more.’
The pattern of younger adults no longer wishing to live with their parents/parents-in-law post marriage is supported by the findings of a recent survey by Presentation Housing in NW Kent. The ‘2000 Black and Minority Ethnic Housing and Community Needs Survey’ reported a significant level of increased demand for separate accommodation amongst younger Asians over the next five years (Presentation, 2000). To illustrate, one 23 year old male respondent stated: ‘... my parents don’t see the boundaries. They think they will just see me saying yes to everything, but frankly I do have a life. I don’t think I will be living with them in five years time, but to them it’s as though I will be living in the same house all my life’ (Presentation, 2000, p63).

The changing profile of the Asian community has implications for service development for older people with dementia and future patterns of family care.

Raising Awareness about Dementia

The ‘Culture and Care in Dementia’ study has powerfully evidenced the positive role and value of educational workshops and awareness raising sessions. A number of issues, related to the development and nature of these workshops, requires analysis and is discussed below.

Imparting information about a stigmatising and hidden illness, that is associated with a host of negative assumptions about the individual sufferer and their family, is a slow and painful process (Lokare, 1999). The importance of balancing a need to take account of the cultural and linguistic milieu, whilst simultaneously offering a different conceptual model and way of viewing support for managing and treating the illness, cannot be overemphasised. Also, offering a number of workshops in different settings, to a range of audiences, over a significant period of time facilitated the educational process. Combining formal presentation with a guided discussion also worked very well. Most people had to hear the message several times before they identified themselves to the project. As the project progressed, more and more community members and leaders, staff and family carers became familiar with the issues and were able to assist with the dissemination of knowledge.

One of the most successful means of raising awareness was by linking into the local Gurdwara in Gravesend. The presentation at the Guru Nanak Gurdwara, which was also broadcast over the radio, reached more people than was expected and led to several carers and concerned individuals coming forward for information and help. The other resource that warrants mentioning is the very effective video - ‘Dementia Ki Hai’ - produced by Alzheimer's Concern Ealing. This video was particularly well received by many older Asian people who could understand and relate to the carers and service users depicted in the video clips.

The effectiveness of raising dementia awareness among the Asian community and introducing the project to GPs, is reflected in the increase in the number of referrals to both the psycho-geriatric service and to ADSS. Nine months after the start of the project, one of the local psycho-geriatricians commented to the researcher that he had had four Asian patients referred to his service in the previous month alone.

One of the most important roles of educating the community about dementia is to prevent neglect of older Asians with the illness (Wilkinson, 2002). The organisation ARDSI, from whom this project sought advice about raising awareness, has identified a number of cases of dementia in India where older people were being ill-treated because of a lack of awareness of the illness among family members. (www.alzheimerindia.org/ardsi_vision.html).

Lack of awareness has also been noted as a cause of neglect in the UK (Killick and Allan, 2001). Whilst the authors have no reason to assume neglect of older Asians is occurring in NW Kent, a number of comments from professionals and carers do raise concerns:

‘Yes, Asian carers do come forward with concerns, there’s an Asian lady in her ninety’s who is at home all day on her own and needs full time care, but the family don’t agree as they are concerned about what people will think’- GP

This project has covered significant ground to introduce the topic of dementia to the Asian community. However, unless measures are taken to ensure that these messages about dementia are repeated, it is the likely that many Asian
elders with dementia will continue to remain hidden and their carers will continue to be unsupported.

Service Development
It is widely acknowledged that simply publicising services and declaring them to be available to ‘all’ is of little value if the services are unsuitable, inflexible and incapable of meeting the specific needs of minority ethnic users and their families (Baxter, 1988). Bould (1990) reported on the experiences of a number of ethnic minority service users - including some Asians - who felt ‘out of place’ in a day centre where activities such as reminiscence groups were geared towards the majority experience of white elders.

In the Study Area, where Asian elders have been placed into a predominately ‘white’ service, it is clear that neither the service users nor the providers are satisfied with the situation; many respondents identified a distinct ‘lack of fit’ between services and the Asian community. We have noted the importance of sharing a common identity and culture with a service and/or its staff. Other important issues include ease of access, limited charges, greater availability of culturally appropriate day and respite care and a greater level of awareness amongst health and social care workers about the lifestyles, health, religious and cultural needs of older Asians and their carers. From their extensive work on various dementia services, Patel et al concluded that in order to provide good dementia services to people from minority ethnic groups, professionals have to be competent in both dementia care and in issues relating to ethnic minorities (Patel et al, 1998; Patel, 2000).

In terms of planning and commissioning future services, findings suggest that at least for the current generation of older people, separate services may be required. Language and cultural issues make this imperative. As noted by one Asian professional:

‘Separate services are going to be needed until mainstream services are culturally sensitive enough... The majority (not all) have financial constraints. You also get the wealthy who won’t spend the money. They fear that Social Services will take away their house etc. to pay for the

service. The younger generation are taking advantage of the situation. They know the state will look after their relative’.

In the Report’s final section the authors move to discussing the implications of the research findings for future service and related developments.
Section 5: Implications and Conclusions

There are two key areas that require discussion in this Section: future service development and training issues for health and social care staff working with older Asians with dementia and their carers.

Commissioning Dementia Services for the Asian Population in NW Kent

New government initiatives have highlighted the needs of people from minority ethnic groups to be able to access appropriate dementia services. This means that the assessed needs can only be met if the services being offered are acceptable to the individual, i.e. they must match the expectations of the service user in terms of the language, culture, religion and spiritual requirements of the individual.

Despite these recent policy developments and the ageing profile of the Asian population in NW Kent, few specialist services have been developed to meet the needs of ethnic minority elders with dementia or those of their carers (Department of Health, 2001). Up until this project only a handful of Asian people with memory problems had presented to dementia services in the local area and all of these were in the advanced stages of dementia. In part, this reflects the hidden nature of dementia in the Asian community as well as an ongoing assumption that Asian families 'look after their own' (Department of Health, 1998).

This project has highlighted a number of specific barriers to service usage that need to be addressed by service commissioners and planners. In the current context, it is clear that Asian elders and their families are only willing to use those services where their linguistic and other cultural needs are met. The fact that these are generic services that are neither appropriate nor resourced adequately for managing people with dementia, is recognised by service providers and, to some extent, users and carers. Good quality care of older Asians with dementia requires competence in both dementia and ethnicity; it is not sufficient to have Asian staff providing care services to Asian users, they also need to have an understanding of the disease and be trained in managing people with dementia.

There are also a number of specific issues around diagnosis and referral on to other services. The hiding of dementia and the somatisation of symptoms by Asian patients make diagnosis of the illness by GPs very difficult. The lack of appropriate assessment tools, the complexity of the referral system and the lack of clear follow up protocols are also unhelpful. A specific criticism relates to limited preparedness amongst GPs to refer Asian patients with dementia to specialist services; this may result from resistance on the part of families to acknowledge dementia in a relative but the present situation is denying expert help to older Asians with dementia (Seabrooke and Milne, 2003). GPs need to be aware of the control they assert over the access to other services by their patients; they also need to be aware that not making a referral may actually lead to failing a patient. The increase in referrals of Asian patients to the psycho-geriatrician over the project period, does suggest that raising the profile of the whole issue helps ensure access to secondary or specialist services. On a related note, GPs unequivocally held the view that they would find training in the specialised field of dementia and its diagnosis useful.

In addition, there are barriers intrinsic to the Asian community. People from this community need to recognise that dementia is an illness and accept that it is not to be ashamed of. Furthermore, the community needs to understand that the quality of life of dementia patients and their carers can be greatly improved by accepting help and services from local providers. The findings of this project have clearly illustrated the benefit of raising dementia awareness through workshops and focus groups among the community members. However, unless there is ongoing investment in an educational cycle incorporating this type of workshop, learning and information sharing will cease and there is a risk that Asian elders with dementia and their carers will revert to cultural norms and slip back to being hidden and marginalised.

In terms of specific services, Asian respondents have stated what they would like to see developed. It is evident that carers find day care very useful and would also benefit from respite
care that is culturally appropriate. These services enable carers to work and/or tend to their own families. To date, service planners in NW Kent have tended to be largely reactive; they now need to become more proactive in identifying and addressing the needs of older Asians with dementia and their carers. Many carers are supporting a relative with 24 hour needs and are under considerable strain; the fact that they feel unable to ask for help is a consequence of pressure from their own community as well as a lack of appropriate services for themselves or their relative (H.M Government, 1999).

In Kent, the County Council has a specific commitment to meeting the health and social care needs of older people from BME communities (Kent County Council, 2002). Included in its service development plan is a joint proposal between Dartford, Gravesham and Swanley PCT and Kent County Council Social Services Directorate to implement a new model of Health and Social Care for Older People in the Gravesham area. The ‘Gravesham Community Project’ will redevelop the Gravesend and North Kent Hospital site. The aim of this is to provide innovative and culturally sensitive health and social care provision, that promotes the independence of older people. A part of this development includes specific services for ethnic minority elders including those with dementia. The proposed provision includes ten residential care beds and a social services day care service for seventy users per week. Although construction work for the facility has not begun yet, the service is planned to be operational at the end of 2005.

Another service development emanates directly from need identified as a consequence of the ‘Culture and Care’ project. Through collaborative working with a range of care agencies over the course of the project, ADSS has developed a proposal to provide an outreach and awareness raising service together with an appropriate and culturally sensitive day care service for older Asians with dementia. It is planned that the day care service will be based at Presentation House in Gravesend and will be a joint venture between ADSS, Presentation House and Kent Social Services Department. ADSS is currently seeking funds to develop such service provision.

Although these are positive developments, considerable gaps in both health and social care services remain, not least of which is developing a clear care pathway for older Asians with dementia and their carers at every stage of the dementia trajectory (Department of Health, 2001).

Training Issues for Managers and Service Providers

Training and education of staff has a key role to play in facilitating change and encouraging accommodation of ethnic minority needs and practices. Certainly research in the field of dementia care identifies training around cultural awareness as ‘inadequate for many managers and staff throughout the health and social care system’ (Daker-White et al, 2002). This project’s findings reinforce this view.

Whilst Kent Social Services is aware of shortfalls in race and equality awareness amongst its staff, more needs to be done to address the specific issues around dementia and culture in the Asian community. Themes include:

• Communication issues are particularly acute for people whose first language is not English; even if they speak English they are likely to lose this skill when they develop dementia
• In order to deliver effective care to older Asians with dementia and their carers, staff need to appreciate the cultural and religious context of ‘need’ and the significance of customs
• Whilst Asian elders have particular cultural needs, e.g. for diet and hair care, individual needs also vary considerably within populations and across communities
• The needs of families and carers have to be recognised and addressed alongside those of the person with dementia. As older Asians often live with their children, it is crucial to work with them in accessing care and designing care packages.
• Ongoing training and support is needed for staff working in all services that serve older Asians with dementia. Staff in ‘generic’ services, such as day care for physically frail elders or specialist Asian services, can often feel unsure of how to deal with dementia issues. Emphasising the importance of
communication and individualised person-centred care is crucial (Kitwood and Brendin, 1992).

- Recognising the importance of confidentiality is a very important issue for all staff but may be a particular issue for Asian staff who may tend to regard the boundaries between the ‘personal’ and the ‘professional’ as rather permeable.

Whilst sharing the same ethnic background as service users can be useful, it is the understanding of the language and customs and the ability to be empathetic to individual needs and sensitive to carers that are key characteristics of a good worker in dementia services. These may not be training issues per se but are about staff appointments, job descriptions and roles. It is also important to recognise that these issues are not located only at the front line; it is equally relevant to raise awareness and educate managers and service commissioners.
Reflections on the Project

No report would be complete without reflection on the project’s strengths and weaknesses.

Certainly, this research study has resulted in an innovative piece of work being carried out successfully within a discrete Asian community in NW Kent. It has begun the important process of shifting perceptions about dementia within the community and has led to increased awareness of dementia related needs and service deficits. It instigated a rapport between ADSS and minority community groups and other organisations supporting Asian elders; it has also promoted understanding of the needs of older Asians with dementia among service providers and commissioners. The reasons for the under-representation of older Asians in dementia services have been identified and the barriers have been located as lying both within the service system and the Asian community itself. Further, the project has generated data that should be useful in the planning of services to meet the needs of Asian elders with dementia and has contributed to the research literature more widely. A number of the messages and conclusions of the work are also of value to care agencies and Asian communities on a national basis.

More critically, the project team had not anticipated the complete lack of awareness of dementia issues in the Asian community at the start of the project. Much time had to be spent raising awareness and challenging the stigma associated with dementia, before people felt able to come forward with their concerns. As a result, the interviews with respondents, particularly carers, began later in the project than was planned and delayed the analysis of the findings. In fact a small number of people who came forward later on in the project could not be interviewed due to time constraints. Another issue related to carers. For some, speaking to the project researcher was the first opportunity they had ever had to discuss their concerns about caring and the needs of their relative. Many welcomed the opportunity to talk. This resulted in the interview not only being considerably longer than anticipated but also rather challenging to conduct as carers shared a wide range of information, some of which was not directly relevant to the project.

The number of GPs who agreed to be interviewed was rather small; canvassing and following up GPs consumed a great deal of time. However, the reported findings were supported by significantly more GPs than the project interviewed via wider discussions and meetings. Finally, despite many attempts to secure interviews and repeated reminders to complete the questionnaires, the research study is lacking the input of some key service managers from Kent Social Services Department.
Conclusion

The ‘Culture and Care’ project has explored a challenging and complex issue within an Asian community in NW Kent that has remained largely invisible to dementia care services since the community was first established in the 1940’s. The project has broken new ground and established a bridge between service providers and the community, as well as opened up a discourse about dementia with community members, service users, carers and service providers.

The project identified clear evidence of dementia related need amongst older members of the community and their families. It also identified barriers that exist within the community itself and the service system, which will require ongoing attention if effective and culturally acceptable services are to be developed. Investment in awareness raising and information workshops is vital, as is training for health and care providers - including GPs - around dementia and culture in the Asian community.

There is significant potential to take forward the work started by this project. It identified a genuine concern among service providers to meet the needs of the Asian population effectively. Kent County Council is also committed to providing effective services for people from BME communities living in its area and has embraced the challenge of introducing culturally sensitive care for older people (Kent County Council, 2002). However, with regard to dementia care for the Asian community, there still remains a significant gap in provision.

In light of the growing number of older Asians with dementia in NW Kent, it is imperative that health and social services commissioners and providers adequately resource existing services to ensure they meet their specific needs. There is also a need to review the possibility of developing separate services where necessary. There is a linked need to extend, and ensure access to, support services for Asian carers.

This service development challenge requires more than simply offering mainstream care to all regardless of age, race, religion or culture. It requires a coherent and focused multi-agency strategy to educate, inform, engage, ensure access to, monitor effectiveness of and assure quality of services that meet need in an acceptable and culturally appropriate way. Working in partnership with the Asian community is a core dimension of this strategy, including taking account of the views of frail older people, carers of people with dementia and current BME workers and service providers (Okuyiga, 1999). Existing commissioning structures may need to review how far this is facilitated at present; the role of ongoing outreach work with the community is also a vital component.

Overall, the project provides evidence of dementia related need, clear direction of specific ways to meet that need and a framework for working with the Asian community, which takes forward dementia education and informs service development. It is essential that the work of this project is taken forward alongside existing service development to ensure that the needs of older Asians with dementia and their carers are effectively met in NW Kent.
1 The Project

1.1 Background Information on Ethnicity & Dementia

Little is known about the prevalence and management of dementing illnesses in minority communities. At present, those who are developing dementia belong to the generation which immigrated to the UK; they are thus much more likely to speak their language of origin, have limited knowledge of dementia and have limited contact with services.

Although ethnic minority carers appear to contend with similar types of symptoms arising from dementia, a recent investigation of 30 carers from ethnic minorities found that awareness of dementia was relatively sparse, particularly among South Asian carers. Most of the carers were looking after relatives with advanced dementia without formal support. This appears partly due to a general lack of awareness of services but also to fear of institutional racism and poor quality of provision. A recent SSI inspection of services to people from ethnic minorities found that many areas were providing inadequate support to older people with mental health problems and their carers.

A number of recent policy documents - most notably the National Service Framework for Older People - prioritise meeting the mental health needs of older people from ethnic minorities and their families. In particular the report states that: ‘Older people from black and ethnic minority communities need accessible and appropriate mental health services’ and emphasises the importance - and effectiveness - of identifying dementia at an early stage.

1.2 ADSS and North West Kent

The charity ‘Alzheimer’s and Dementia Support Services’ (ADSS), based in Gravesend, North West Kent, is a relatively small voluntary organisation which offers practical and emotional support to people with Alzheimer’s disease and other dementias, and their carers.

The Foundation has chosen to partner ADSS as:

- Its experience of attempting to open up its services to minority ethnic groups illustrates many of the issues identified above. While the area contains a significant Asian population (5.3% rising to 8.4% in Gravesham, Census 1991) neither Asian older people nor their families make use of the ADSS. Attempts have been made to make the services more accessible to this group: for example, ADSS have translated some information into Punjabi and have spoken with the providers of services in the locality which do offer support to Asian older people with dementia. However, to date, these efforts have been unsuccessful.

- There is a voluntary and statutory network in the area, which provides a good platform for exploring the wider issues of policy and practice. ADSS has links with the local ‘Race Equality Council’ and the Dartford & Gravesham ‘Ethnic Forum for Mental Health’ a multi-disciplinary policy and strategic planning forum. These bodies and local social services departments (which provide two-thirds of ADSS referrals) have recognised the need for an effective early intervention service for the Asian community - perhaps through adapting and/or extending ADSS’s services.

1.3 Aim

To better understand the needs of older Asians with dementia and their families in order to ensure the ADSS and other services meet needs more effectively and to influence local - and where appropriate national - policy and service development in this field.
1.4 Objectives
On a local level, through the project in North-West Kent
• Identify the nature, extent and mental health needs of the older Asian population
• Identify the services Asian older people with dementia (and their carers) access and which kind of support they offer
• Identify what Asian older people and their carers want from services and how ADSS could adapt/extend its provision to this community

1.5 Process
• Conduct a ‘mapping and fact finding’ exercise on the current needs and services for the older Asian population in North West Kent
• Draw together the issues that need to be addressed to develop effective services for older Asians with dementia and their families

1.6 Timetable:
• Months 1-6 Awareness Raising Activities & Review of Population Need & Services
• Months 6-18 Sampling & Conducting Fieldwork
• Months 18-20 Data Analysis & Mapping the Dementia Related Needs of Asian Elders and their Carers
• Months 21-24 Writing Project Report and Disseminating Findings

1.7 National Relevance
The project findings and outputs will be of significant relevance to wider UK service developments in two ways.

1.7.1 They will be of specific value to those agencies developing - or considering the development of - services to meet the needs of Asian older people with dementia and their families. The ‘lessons learned’ about raising awareness and facilitating access to dementia support services by older Asian people and their carers will be particularly useful. Services for older South Asian people with dementia and their families/carers are underdeveloped in the UK and a project of this type will be able to offer guidance and a framework for effective service development.

1.7.2 Secondly, the outcomes may be useful to services being developed to meet the dementia-related needs of other ethnic minority groups. Although the focus of the project is on a South Asian community, the project’s outcomes will have wider implications for ensuring the cultural appropriateness and accessibility of services for older people from a range of ethnic minorities. This is valuable from both a service development and policy perspective (Department of Health, 2001).

1.8 Structure & Management of the Project
The researcher is of Asian origin and speaks Hindi & Punjabi. She is based at ADSS in Gravesend and is managed by Carol Smith, manager of ADSS, with research supervision provided by Alisoun Milne (Consultant, Mental Health in Later Life Programme & Senior Lecturer in Social Gerontology, University of Kent).

1.9 Period of Project
The project is running for a 24 month period from February 2002 to January 2004.
Appendix 2

Needs of Asian older people with Dementia and their carers in the Dartford and Gravesham area

Guidance Questions: Interviews with General Practitioners

Section 1: About the practice

- Name and address of GP and the practice:
- Size of Practice: No. of doctors, patients and practice nurses
- Ethnicity of the various staff at the practice (clinical & admin)
- Languages spoken (by clinical & admin staff)
- No. of Asian patients at the practice: Total and those over 60.

Section 2: About the patients and dementia

(For all the following questions gather information for both the general population and Asians specifically)

- How often do Asian older people present with memory problems and how does this compare with the rest of the population?
- If there is a difference, why?
- Do you find that Asians tend to present at later stages of the illness?
- What symptoms do Asians bring to your attention if they are not familiar with ‘dementia’?
- How does this differ (if at all) from other groups and why?
- Do the carers come forward with their concerns and if so, is this more or less often among Asians?
- Many older people associate memory problems as a normal part of the aging process. Is this more or less often among Asians?
- How do you respond to people who have accepted the symptoms as ‘normal’?
- How do you deal with people who present with forgetfulness or more specific memory problems? Does this differ in any way for Asian patients?
- What course of action/treatment do you follow for these patients? Does this differ in any way for Asian patients?
- What services are available locally for patients with dementia?
- What services if any do you refer these patients to?
- What information do you have in your waiting area to make patients aware of other services in the area?
- If you deem that a referral is necessary, to which specific professionals do you refer your patients?

Section 3: Views and opinions of the GP

- Are there any gaps in services for people with dementia?
- What additional services would you like to see in place to help with the care of Asians elders with dementia?- for patients and for carers.
- In your opinion could new services for Asians with dementia be integrated into existing mental health services? Yes/No
- If yes, what changes/improvements need to be made to make the existing services to make them more appropriate to the needs of Asian people?
- There is very poor uptake of ADSS services and other dementia services by the Asian community. In your opinion, is this because of a. ignorance about the services b. cultural differences c. language problems d. other reasons.
- In your opinion is there a need among health and social service professionals for further training around dementia and cultural awareness?
- Do you have any other comments?
Appendix 3

Needs of Asian older people with Dementia and their carers in the Dartford and Gravesham area

Guidance Questions: Interviews with Health Professionals & Service Providers

Section 1: About the Department

- Name and address
- Size of team; No. of clients; age group of clients; ethnicity of clients
- Ethnicity of the various staff in the team
- Languages spoken (by staff members)
- How do people access the services?
- No. of Asian clients
- Role of the team
- Services provided and charges for services
- Financed by
- Assessment of needs
- Any work with carer.

Section 2: About the service users and dementia

- If Asian patients are not coming forward for help, why not? What can be done to change the situation?
- How are the services received by people of minority ethnic communities? - What do you do to get feedback on your services?
- What methods are being used to attract clients?
- What issues/ triggers do clients bring to your attention?
- What issues/ triggers do Asians bring to your attention if they are not familiar with ‘dementia’?
- Does this differ from other groups? Why?
- What services are available locally for patients with dementia?
- What other services if any do you refer your clients to?

Section 3: Views and opinions of the Interviewee

- Any literature in foreign languages?
- What are the barriers in accessing your service?
- In your opinion, what can be done to enhance uptake of services by the ethnic minority clients?
- In your opinion could new services for Asians with dementia be integrated into existing services? Yes/No
- If yes, what changes/improvements need to be made to make the existing services to make them more appropriate to the needs of Asian people?
- What additional services would you like to see in place to help with the care of Asians elders with dementia?
- Is there a need for specific services for carers?
- There is very poor uptake of ADSS services and other mental health services by the Asian community. In your opinion, is this because of: a) ignorance about the services; b) cultural differences; c) language problems; other reasons
- Is there a need among health and social service professionals for further training around dementia and cultural awareness? (give examples)
- Do you have any other comments?
Appendix 4

Needs of Asian older people with Dementia and their carers in the Dartford and Gravesham area

Guidance Questions: Interviews with Carers

Section 1: Client details
- Name, Address, Telephone & ID number:
- Date of birth or Approx. age
- Ethnicity
- Languages (spoken/read)
- Name of GP
- How long have you lived in: a) Britain b) Current Area
- What are your disabilities/illnesses?

Section 2: About the household
- Who lives in the house with you and do they have any disabilities or chronic illnesses? (Record relationship, age and any disabilities or illnesses)
- Do you see anyone else on a regular basis, e.g. neighbours, friends, relatives etc?
- How is your care organised within your family

Section 3: About the service user
- How has the illness affected you? What can’t you do now that you used to be able to do before?
- How is your care organised within your family
- Please describe your daily routine
- Have you ever been offered any of the following medicines: Remynil, Exelon, Aricept or Maxalon?

Section 4: About the carer(s)
- What help are you getting?
- Do you receive any support from services or from other family members?
- What are your coping strategies?
- What help would you like?
- What help have you tried to get?

- What difficulties have you encountered in trying to get help, e.g. language, religion, food, financial, culture, stigma, family members objecting to outside help, barriers within the system and others.
- Do you feel you’ve been given enough information about your relative’s condition and how to manage it?
- What issues have you been concerned about and spoken to your GP about?
- What information have you been given about services for: a) yourself and b) your relative?
- Which services have you contacted and what services have been put in place?
- Would you or your relative use any of the existing services such as: (with reasons) Residential homes, day centres, Sahayak, ADSS, Crossroads, Age Concern, district nurses, social services, homecare, hospital or other?
- What additional service would you like for the care of your relative?
- Do you know what benefits you are entitled to?

Section 5: With hindsight
- What help and information do you wish you had had when you first realised that something was wrong?
- What kind of help, e.g. homecare, respite, medical, hospital, etc. would you have liked?
- Who do you think the services should be provided by- Asian specialist services or general services? a) for current generation and b) for next generation?

Section 6: About ADSS
- Which of our services would you find useful?
- Which would you not find useful?
- How could ADSS extend its provision to take account of you and your relatives needs?
- Any other comments?
A Workshop on "What is Dementia?"

On: Wednesday 20th August 2.00-4.00pm
At: The Guru Nanak Darbar Gurdwara
Clarence Row
Gravesend.

To book your place please complete the form and place it in the envelope provided on the notice board at the Gurdwara.

Name

Telephone No:

Number of places required: _________


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Further copies of the report are available from:

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www.mentalhealth.org.uk

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