



PRIAE in collaboration with ISCRI, International School for Communities, Rights and Inclusion, University of Central Lancashire

PRIAE – ISCRI Managing Better Mental Health Care for Black & Minority Ethnic Elders

A 5 Part Guide:

- PRIAE in Mental Health
- Elders and Carers Guide
- Mental Health Assessment Guide
- Examples of Good Practice in the Provision of Mental Health Care for BME elders
- PRIAE Films on Dementia, Active Ageing, Volunteering, PRIAE-Policy

Department of Health S.64 funded project

PRIAE 12 years: Passion, Pride & Progress in ageing, ethnicity and migration

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Registered Charity No: 1081930 Company Registration No: 3898974

ISBN: 978-09537642-6-6

These resources are produced as a result of the PRIAE Department of Health funded project 'Managing Better Mental Health Care for Black and Minority Ethnic Elders' designed by Professor Naina Patel OBE, Executive Director of PRIAE and author of Part 1.

The project was delivered on behalf of PRIAE by Jez Buffin at the International School for Communities Rights and Inclusion (ISCRI) at the University of Central Lancashire. Special thanks are due to: Alia Syed, Joanne Hicks, Imran Mirza, Yaser Mir, Nadia Ahmed, Naomii Oakley and Khalil Patel.

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Part 4 was written by Nicole Crompton, Lecturer in Equality and Diversity at the International School for Communities Rights and Inclusion at the University of Central Lancashire.

Various people and organisations that made this work possible are acknowledged under each section.

Part 5 presents PRIAE's acclaimed films on Dementia (UK-European focus); Active ageing; BAFTA launched film on Volunteering; PRIAE-Policy narrated by Jon Snow and produced by Move a Mountain

Published PRIAE and ISCRI,
University of Central Lancashire,
Preston UK



About PRIAE

PRIAE (pronounced 'preeya') is a not-for-profit, independent international charitable Institute, established in 1998. As the only international organisation specialising in ageing, ethnicity and migration, PRIAE occupies a unique position and plays an essential role in policy, research, information and practice on:

- **Employment, Enterprise and Income;**
- **Health, Social Care and Housing;**
- **Citizenship and Quality of Life**

PRIAE's aim is to develop the area of ageing, ethnicity and migration with leading developments that help benefit minority ethnic older people. PRIAE has since its founding in 1998 pioneered considerable progress in diversity and equality in employment, pensions, health, social care, housing, enterprise, organisational development and leadership. Consequently many of its initiatives are considered 'first of its kind' and have stimulated further developments by others to expand the field of ageing and ethnicity.

PRIAE's flagship projects and products since 1998 include: Seminal policy report to the Royal Commission on Long Term Care for the Elderly; Largest research on minority elderly care in Europe covering 10 countries and 26 ethnic minority groups (MEC); Study- film on dementia (CNEOPSA); Active Ageing (AIM); Palliative Care (PALCOPE); Policy Network (ME²PN) ; Contribution to Ethnic Minority Employees to Small & Medium Size Enterprises (CEMESME)/(READi); Dignity in Care; Housing; MiLEON Minority Ethnic Leadership.

PRIAE was founded in 1998 by Professor Naina Patel OBE who recognised the need for a dedicated organisation that focused and concentrated on the various issues faced by Black and minority ethnic elders and their organisations amid increasing population change and slow policy and practice developments. Naina built PRIAE up with zero finance and with support from a distinguished Management Board, chaired by Lord Herman Ouseley, Vice Chair Lord Navnit Dholakia, Liam Hughes Treasurer, Professor Sashidharan and Jeffrey Greenwood and, later, staff when longer term funds were secured in year 2001, to the international organisation it is today. PRIAE has its first patron, Dr Chai Patel, CBE, FRCP.

Please visit us at www.priae.org



About ISCRI International School for Communities, Rights and Inclusion, University of Central Lancashire, Preston, UK

Led by Professor Lord Patel of Bradford, OBE, the **International School for Communities, Rights and Inclusion (ISCRI)** aims to be the foremost higher education School in the UK and internationally dedicated to the cross-disciplinary, multi-cultural, academically rigorous study of the interface between individuals and society at a time of significant global uncertainties.

By blending taught courses with research and project work ISCRI aims to be a strong national and international voice for equality and human rights, challenging injustice, and seeking to ensure the voice of users is heard by all types of institutions. The School runs a range of undergraduate and postgraduate taught courses and has opportunities for research to Masters and PhD levels in all the subject areas and has a vibrant and extensive research and consultancy programme in all areas of activity.

ISCRI was established in August 2008 by the merger of six existing academic units – the Centre for Ethnicity and Health, the Institute for Philosophy, Diversity and

Mental Health, the Centre for Professional Ethics, the Psychosocial Research Unit, the Centre for Volunteering and Community Action, and Islamic Studies. To these have been added the International Institute for Sign Language and Deaf Studies (iSLanDS) and the Inclusion Institute that is taking forward the National Social Inclusion Programme. The School has re-organised into two large Centres and three smaller Institutes, as below:

- Centre for Psychosocial Research and Wellbeing;
 - Centre for Social Policy and Community Engagement
 - iSLanDS
 - Inclusion Institute
 - Institute for Global Youth Leadership and Community Action
-
- In addition the School runs the **Communities, Rights and Inclusion** programme (CORIIN), a major mental health equalities and diversity project in Leicestershire.

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Forewords

Lord Herman Ouseley
Chair of PRIAE

PRIAE Trustee, Consultant Psychiatrist
Professor Sashidharan

In 1998 and in 1999 when PRIAE published its work on dementia and ethnicity, we could reach a conclusion that mental health services to Black and minority ethnic (BME) elders had received little attention. Consequently PRIAE's study into dementia and its translation into an innovative product – an awareness raising European film - were then seen as 'first of its kind'. We have consistently worked with the view that it is insufficient to describe issues and problems that BME elders face. Efforts need to be made to offer workable solutions and that quality care must incorporate language and culture. This is what BME age organisations do across the country to respond to the ordinary needs of elders in their community. They are critical to the well being of elders and PRIAE has long argued for their better funding and resource structure. After all BME elders are part of society and being 'healthy' requires a balance of both physical and mental health. Lack of information and knowledge are seen as key determinants for preventing BME elders from accessing services. We are aware that information alone is insufficient to achieve the necessary changes: how professionals diagnose, plan and treat patients are also significant. So how do we best meet the demands of two different groups in one publication when the area of BME elders' mental health has been under developed?

We are pleased that a decade later we have this comprehensive publication which continues in PRIAE's tradition of applying knowledge with practical resources that can help both: elders and their families, and professionals working in the field. Our colleagues from ISCRI, International School for Communities, Rights and Inclusion at the University of Central Lancashire who helped implement PRIAE's mental health work has given us added strength to present this publication with a clear view: that to make a difference to BME elders' mental health, everyone concerned with the area need to use such a resource – and translate it for themselves to help advance the area further.

This is a five part publication with a collection of films including 'Dementia matters Ethnic concerns' a European first film in the area. The first part of this publication sets the context of PRIAE's work and its struggles to establish the agenda that, like anyone else, BME elders also need support and services when in need. The recommendations derived from its work soon influenced policy – the setting of National Service Framework Standard 7 in Mental Health with specific reference to BME elders and their mental health. This was considerable progress given where we started from. This work also showed the need for step by step guide that would help individuals to better access the mental health system while supporting professionals to think and act in assessments that help individual patients. The second and third part of the publication does this fully both as information and as a working tool. The fourth part gives recognition to many small and specialist age service organisations that have developed responses to meet the mental health needs of elders from their communities. The authors have captured well the information and developments necessary to advance the area of mental health and to improve mental health support and care to all elders.

We thank the Department of Health for supporting PRIAE in its work on mental health and minority ethnic elders. We hope that you will find this considerable resource useful in your endeavours to benefit elders' mental health and well being, today and tomorrow.

Melba Wilson

National Programme Lead

Mental Health Equalities Programme

National Mental Health Development Unit

I am pleased to have the opportunity to welcome this publication by PRIAE (the Policy Research Institute on Ageing and Ethnicity).

The report forms an important contribution in the area of Black and minority ethnic elders mental health; and adds considerably to the knowledge base about what effective work with diverse communities and client groups can and should entail.

The resource takes a modular approach. Firstly providing useful context on the history and development of work in relation to BME elders mental health and the particular issues facing them. A key aspect has been and is the need to increase awareness and thus promote better understanding.

Much of this work has been pioneered by CNEOPSA (Care Needs of Ethnic Older Persons with Alzheimer's) which identified issues of language, culture, information and the complexities of the care system, among other things, as key aspects which should be addressed to improve services. This text takes that discussion forward by highlighting the need for continuing and targeted work to sustain understanding and good practice.

Secondly, the text includes a plain-speaking guide for elders and carers as part of helping their understanding of using specialist services. Finally, the resource focuses on the important area of mental health assessment of BME elders, and the implications for informing and improving planning and service delivery.

The detail provided in each of the modules - for professionals to promote understanding; and for communities to enable them to better access services is both necessary and welcome.

The publication is also quite timely, given the emphasis in New Horizons, the new mental health strategy, with its own better mental health and well-being and non-discriminatory care for older people.

This is the challenge not only for services, but for society, as a whole. This resource, which is the product of collaboration between PRIAE and ISCRI, the International School for Communities, rights and Inclusion at the University of Central Lancashire, is an enabler in helping to meet that challenge.

Professor Lord Patel of Bradford OBE

The proportion of older people in Black and minority ethnic communities has rapidly increased over the last three decades. The prevalence of depression and dementia, the two most common mental health disorders in old age, are either similar or higher in older Black and minority ethnic individuals compared to their indigenous counterparts. Older Black and minority ethnic individuals with mental health disorders are disadvantaged and they do not readily access mental health services. Poor access to mental health services is related to a variety of factors including factors associated with potential patients and their family, primary care and secondary care. Their experiences and outcomes once in the system are also arguably poorer.

Professor Ajit Shah, an experienced clinician working in a multicultural setting, has written two guides in this publication on behalf of PRIAE. The first guide is entitled “Elders and Carers Guide – Use of Specialist Mental Health Services for Older People”. This guide highlights a journey that potential older patients and their carers would take through the mental health system. It meticulously explains various stages during the patient’s journey through the mental health system. This guide, although written with older Black and minority ethnic individuals in mind, is equally applicable to all older individuals; and will be an excellent source of information for older people with mental health problems and their carers. I very much hope that it will help reduce the stigma attached to mental illness, reduce fears about entering mental health services and enable potential patients and their carers to access mental health services and treatment early.

The second guide entitled “Guide – Mental Health Assessment”, provides guidance to multidisciplinary mental health professionals, on planning and development of mental health services for older Black and minority ethnic individuals, and in their actual clinical assessment. It also thoroughly deals with every aspect of planning and delivery of services and the actual assessment of older Black and minority ethnic individuals. This guide will no doubt be of value to all mental health professionals working with older people from Black and minority ethnic communities. It is likely to enhance the knowledge and skills pertaining to mental health issues for this group of older people among multidisciplinary mental health workers. This, in turn, I am sure will lead the way to enhanced provision and delivery of mental health services to this disadvantaged group.

Taken together, both the guides, by targeting potential patients and their carers and multidisciplinary mental health professionals, are likely, not only, to improve access to services, but also importantly improve the experiences and outcomes for older Black and minority ethnic individuals with mental health disorders.

They are augmented by the fourth part of this report which highlights a number of examples of good practice in the provision of mental health care for BME elders. These examples were derived directly from the experiences of BME elders who told PRIAE the kinds of things that they valued in care and gave examples of services where these had been provided.

The inclusion of four films then completes this major resource contribution to the area.

PRIAE has been, for that last decade at the cutting edge of identifying, commenting on, designing and developing key policy and practice issues for Black and minority ethnic older people, and this is yet another key product in its armoury. Once again PRIAE should be congratulated in commissioning another important piece of work to improve the lives of Black and minority ethnic older people.

PART 1

Introduction

**PRIAE – Establishing
Black and minority
ethnic elders' mental
health work**

PART 1 Introduction

PRIAE – Establishing Black and minority ethnic elders' mental health work

1. Establishing the agenda and influencing practice

This publication brings together work of several years and people who have contributed to the development of mental health among Black and minority ethnic (BME) elders. PRIAE is credited for 'pioneering' the agenda and so the first part takes the reader through this journey briefly since progress takes more than time, effort and resources. Looking back from this year 2009, we have come a long way, in a short time. BME elders are seen not only to exist and be growing in numbers, but to have mental health needs. This is in contrast to what was said a decade ago for example in 1998,

'Minorities? We just had not thought of them...but now that you mention it we think it is relevant.....'
-several respondents who provide services and training (from the EACH project)

'The world of dementia is colour blind; the world of black and minority organisations is dementia blind'
- Professor Mary Marshall in the foreword to the CNEOPSA study 1998 (Patel N, Mirza, N et al *'Dementia and Minority Ethnic Older People - Managing Dementia Care in the UK, Denmark and France*, Russell House Publishing)

There was clearly a void in the area with some exceptions. The quote above was central to the transnational CNEOPSA (Care Needs of Ethnic Older Persons with Alzheimer's) project begun by PRIAE's Executive director with European Commission funding in 1997-1999. It informed mental health work at PRIAE (Policy Research Institute on Ageing and Ethnicity), an independent international institute specialising in work with older people from BME communities. It was as a direct response to the huge gap in services for, and policy about, older people suffering with dementia from minority groups in Britain that the CNEOPSA project was conceived. When the work started in 1997, a literature review revealed that there had been fewer than 5 publications on the subject of dementia within BME groups and a similar paucity of research projects investigating the multiplicity of issues surrounding dementia within these populations. The research agenda at this point was clear:

- To alert BME groups, mainstream service providers and policy makers to the existence of older people

- with dementia within minority populations.
- To develop appropriate policies and services for BME elders with dementia.
- To start filling research gaps via reference to a wide range of literature within the UK and from abroad.

The CNEOPSA study is regarded as the *'first attempt to deal systematically with ethnic minorities and dementia'* (European Commission, 1998). The study did not look for comparisons on whether 'minorities have more / less dementia than the majority population'. Rather, the key issue concerned that dementia exists; and what is being done about it given the knowledge of under-developments in the area for BME elders. In the process it recognised individuals and organisations providing services in the area. The CNEOPSA project considered all the key players in the system of care: the person with dementia, family and professional carers, mainstream care providers, minority ethnic organisations, majority voluntary organisations, and policymakers to design its initiatives as well as its delivery.

The CNEOPSA study findings can be summarised as:

- **Language** – dementia sufferers and their families who do not speak English face problems at every stage when trying to get care.
- **Information** – minority ethnic families are unable to communicate with care professionals or are not able to access information on what services are available to them.
- **Culture** – many cultures fail to recognise that dementia is an illness. Because of this issues are not addressed and dementia is accepted as an inevitable part of growing old. Cultural problems also account for families tending to look after the person with dementia themselves and not trying to get outside help. This leads to the person coming to the attention of care professionals later in the illness.
- **Complexity of the care system** – minority ethnic people with multi-faceted illnesses such as dementia who are, in addition, disadvantaged by language and the cultural stigma associated with disease in old age, face huge problems in negotiating a very complex system which involves several agencies with their own methods of working.
- **Funding for care provision** – the inadequate and short-term nature of funding is a particular problem for day centres and voluntary organisations, which impedes their ability to provide services. Since day centres may for various reasons (see above) be better placed to provide care for minority ethnic elderly with dementia than residential centres, this is yet another barrier that they face.

- **Specialist organisations** – analysing the current context of care for minority ethnic elderly and the critical position of minority ethnic organisations in providing this care, a recommendation for further specialist organisations as an area of development appears to be a sensible pragmatic solution. These organisations are already on the ground providing this care. Not only do such organisations recognise the current unmet need in these communities but also it is estimated that in the near future there will be higher numbers of older people from such communities.
- **Training and materials development** – it is clear from these findings that organisations want training ('specialist advice and support' in working with professionals) and 'appropriate' resources to support existing materials in how to care for people with dementia and to understand more about the clients culture and background.
- **Policy and Research** – all organisations regarded these two areas equally worthy of immediate development.

CNEOPSA findings have implications for various organisations and people across health and social care sectors. The essential strategies required are:

- Targeted developments and research must be put in place to assist ethnic minorities in accessing dementia care, as this has been so impoverished in the past. The involvement of mainstream statutory and voluntary providers is crucial due to the resource limitations of the dementia sector as a whole.
- An information and communication strategy needs to be put in place to increase awareness of dementia and support for carers. A number of cultural barriers continue to prevent ethnic minority groups from recognising the onset of Alzheimer's or seeking outside help.
- A training package needs to be put in place for health and social care professionals, allowing them to engage with the issues and develop their own appropriate strategies. PRIAE has begun running such sessions, and the support we have received indicates a willingness of health care professionals to participate.
- Mainstream organisations need to employ specialist minority ethnic workers, who are well placed to ascertain needs and anticipate problems. This would also help to stimulate appropriate care developments for the future.
- Policymakers need to recognise that minority ethnic organisations are essentially acting as primary

providers of care in the absence of mainstream services. This should be reflected in future funding arrangements, as they currently suffer from scarce and short term resources.

This work from the CNEOPSA project allowed for PRIAE's inclusion to the task group that formulated the National Service Framework (NSF) for Older People Standard 7, published in 2001. The Institute played a key role in securing recognition of the shortfalls in provision for mental health patients from the ethnic minorities, as enshrined in one of the key documents driving forward improvements in the National Health Service.

2. Moving from agenda setting to increasing awareness and knowledge

Policy makers need to *implement* policy that extends the area of mental health to BME elders. Professionals need to consider the barriers and difficulties which exist, have appropriate culturally sensitive training, and where necessary employ specialist BME workers in organisations. Whilst family carers need to understand and be more aware of dementia/mental health, they need support and information as do voluntary minority age organisations since they directly provide care and information to BME elders. From all these perspectives and scarce resources, the CNEOPSA project concentrated on one of its recommendations, that is, to increase awareness and to take action to develop culturally appropriate knowledge and practice in dementia care, for the benefit of minority ethnic elders. This was translated into a European film to inform elders and carers, as well as act as catalyst for early referrals. This film, *Dementia matters Ethnic concerns* which is aimed at BME elders, professionals and policy makers sets the context for key issues to address in BME dementia care. This film spurred further developments where two ethnic specific films were subsequently made - one for Asian elders by Alzheimers' Concern Ealing and for African Caribbean Elders by Alzheimer's Society. They represent an important advancement in a short span of time (3 years). Previously no tailor made information to BME elders and professionals existed except for leaflets translated. Post 1999, concrete (and motivating) information products have been generated to be used in developing appropriate care to BME elders in years to come.

For example, the CNEOPSA film has been regarded as critical in increasing referrals to a dementia centre (Wolverhampton, 2001).

'The Policy Research Institute on Ageing and Ethnicity, with its European partners is to be commended for adding an impressive tool to its flagship project CNEOPSA, in minority ethnic dementia care.'
- Rt. Hon. John Hutton MP, Health Minister, UK 1999

3. Assessing patients, strengthening organisations and advocacy & training

The CNEOPSA project at PRIAE has adopted a 'system of care' approach encompassing all aspects which relate to the person with dementia and the carer. Having established the urgency for agenda setting and information development (1998- 2000), PRIAE set itself three key developments (2002 to date): assessment; capacity building in BME age organisations and advocacy and training of BME elders and professionals. This is supported by policy context: the DH action plan on 'Delivering Race Equality in Mental Health Care' was launched in February 2005. Explicit recognition is given to the additional barriers faced by older people from BME groups and the need to support this area of work. For PRIAE this means from access/referrals to information/communication to capacity building in knowledge, delivery and dissemination of appropriate mental health services.

a. Assessing patients in dementia:

PRIAE commissioned Professor Shah to outline assessment and diagnostic issues since this is an area that PRIAE has been consistently asked for advice by mental health professionals. This work will help to support mental health professionals and help BME elders and families to better understand the assessment process and diagnosis. This is in part 3 of this guidance report. This work represents an important milestone in PRIAE's systematic building of information, knowledge and practice as part of the agenda to invest in mental health of BME elders today.

b. Strengthening organisations that support elders

BME age organisations are regarded as 'critical' to meeting BME elders' care and quality of life (Patel, N 1990, *Race Against Time? Social Services Provision to Black Elders*, Runnymede Trust; Patel N 1998 *Perspectives on Long Term Care*, Royal Commission on Long Term Care for the Elderly, HMSO). BME organisations highlight two barriers that BME elders have to overcome in getting dementia care/mental health support. The first communication barrier means that BME elders have difficulty in attaining the same level of services as elders from the majority group. This means that BME elders are either sent home or, if they do acquire a care service, are confronted by secondary cultural barriers in a mainstream setting. For example, minorities as people have different habits, religious needs, food requirements, and wishes. Specific barriers to obtaining services include language, lack of resources (e.g. assessment facilities) and information, and the stigma of the illness being a form of madness. In addition the complexity of the system of care is itself a barrier. To overcome difficulties BME organisations are obtaining more information on dementia/mental health, increasing practical training for staff, encouraging

more inter-agency co-operation, improving staff-staff and staff-client relations (empathising with the person with mental health problems, helping in family difficulties and making families aware of services available to them), and adding resources (e.g. bilingual staff). Information programmes directed specifically at carers and families are important in overcoming difficulties. For example, helping families identify and appreciate the early signs of dementia. As part of engaging with BME organisations which is a normal process for PRIAE, investing in a few identified BME organisations with new methods, tools and skills, is being developed and adapted. This allows for the potential transfer of knowledge and practice between BME organisations and mainstream service providers, thereby accelerating progress in mental health of elders.

c. Advocacy and Training

Training and materials development were identified as important actions to undertake in the CNEOPSA study and the film.

4. Conclusion

The implication of PRIAE's work in dementia/mental health in ten years is that while the area has been lifted where it is regarded as important and included in the National Service Framework for Older People and Delivering Race Equality in Mental Health for example, much remains to be developed as well as financed. This raises several issues particularly equity in mental health care and support to BME elders.

The approach at PRIAE working with individuals and organisations, has been one of systematic development of specific recommendations arising from its CNEOPSA study published in 1998. The developments are to increase information, capacity and confidence; have appropriate assessment and receive clear communication - among those who need services and those whose responsibility it is to commission, design, develop and deliver effective mental health practice and care. Minority ethnic elders and professionals engaged in PRIAE's work have contributed to its achievements and look to further progress that makes mental health support to BME elders a normal process rather than one of occasional interest.

The next three parts on guidance for elders and carers, assessment and good practice are a major contribution towards this continuous development of the area and in turn individuals and families who may seek specific information resources to assist them in time of need.

PART 2

Elders and Carers Guide

Use of Specialist Mental Health Services for Older People

Preface

This guide was developed for BME elders who may use specialist mental health services for older people at the request of the Policy Research Institute for Ageing and Ethnicity for a Department of Health funded project. It will also be of value to their carers. This guide was developed with input from a carer, an ex-carer, colleagues from a local voluntary sector organisation and clinicians working in specialist mental health services for older people. Although the guide was designed with BME elders in mind, it is written in a style that will be of value to all elders who may use specialist mental health services for older people and their carers.

Acknowledgements

This guide was conceived by PRIAE as a result of its earlier work and listening to the many voices of elders, carers and staff from minority age organisations' attending PRIAE events in mental health and/or PRIAE staff attending mental health events during the past few years. They acknowledged that there exist several information resources on mental health for older people. However a guide that answered to their questions would be a useful resource not just for minority ethnic elders but for all. It is with this aim that this guide was prepared by Professor Ajit Shah and our special thanks are due to him.

Several individuals assisted in commenting on the original draft of this guide and helping to improve it. Our appreciation and thanks to

- From Alzheimer's Concern Ealing, its Chairman Hugh Randall who is an ex-carer and staff members Francis English and Kulbir Gill
- From West London Mental Health NHS Trust, Vijay Kumar, Community Psychiatric Nurse; Bala Poinasamy, Staff Nurse; Abel Koshy, Trainee Psychiatrist
- An anonymous carer.
- PRIAE staff and consultant Michael Lee and Arnfrid Beier in particular for Appendix 1

We hope that in turn this guide will inform and help individuals be better prepared to access mainstream and specialist mental health services. We hope that you will use this guide and encourage others to refer to it. We welcome your comments. Please send to **info@priae.org** or **ajit.shah@wlmht.nhs.uk**

Professor Naina Patel OBE
Founder and Executive Director of PRIAE

1. Background

This guide follows a journey of a BME older individual with potential mental health problems through the health service. It provides information on a range of issues that may be encountered by BME older people and their carers following this journey by using a question and answer format. Although the guide is written from the perspective of a potential patient, the information contained in the guide will also be helpful to carers.

2. What is old age?

The cut-off age of 65 years will be used for old age in this information guide. This age cut-off is used because most specialist mental health services for older people use 65 years as the age cut-off for individuals, including those from BME groups, to enter the service.

3. What are Black and minority ethnic groups?

There are several definitions of BME groups. Two commonly used definitions are given below:

- The definition of BME groups used in the governmental document *Delivering Race Equality in mental health care* was "... all people of minority ethnic status in England. It does not only refer to skin colour but also to people of all groups who may experience discrimination and disadvantage, such as those of Irish origin, those of Mediterranean origin and East European migrants".
- Another useful definition of BME individuals is "those with a cultural heritage distinct from the majority population".

Although there is no universally accepted definition of BME groups, the above two definitions are pragmatic in clinical practice.

4. How common are mental health problems in older people from Black and minority ethnic groups?

Dementia and depression are the two most common mental disorders in old age. Over 5% of people over the age of 65 years have dementia. About 15% of people over the age of 65 years have depression. Both these disorders are at least as common in older people from a range of BME groups as they are in indigenous white British older people. There are 531,909 older people from different BME groups in England and Wales. Up to 11,860 older people from BME groups have been estimated to have dementia. Up to 52,980 older people from BME groups have been estimated

to have depressive illness. Thus, mental disorders are not uncommon in older people from BME groups.

5. How can mental disorders be recognised?

Dementia is a disorder that can affect memory, mood, behaviour and day to day function. The dementia-sufferer may present with:

- Forgetfulness (initially for recent events but as the illness progresses this may also occur for older events).
- Being muddled and confused.
- Disorientation in time, place or person.
- Inability to perform tasks which the individual would normally have been able to perform. When it is severe they may be unable to wash and dress themselves, cook, do the housework, go shopping and use the telephone, and forget to take medication and keep appointments.
- Losing their way and getting lost.
- Forgetting to turn the gas off or taps off or close the door shut.
- Changes in personality whereby their normal personality may be exaggerated or they may develop new personality characteristics.
- Behavioural problems including reduced sleep, agitation, aggressive behaviour and pacing.
- Depressive symptoms (they are described below in the section under depression) and sometimes depressive illness.
- Delusions of persecution (e.g. they may believe that others are stealing their belongings).
- Misidentify events around them (e.g. they may believe intruders are living in their house, may not recognise themselves in the mirror, may not recognise familiar faces and may feel things happening on the television are happening in their personal space).
- Auditory or visual hallucinations – hear voices or see things which are not there.

The above symptoms are not exhaustive but they are some of the more common ones.

Depression is an illness that affects the mood of the patient. Range of symptoms of depression includes:

- Depressed mood.
- Feeling sad, unhappy and despondent.
- Crying.
- Loss of appetite and loss of weight.
- Sleep disturbance including difficulty in going to sleep, broken sleep and waking up very early.
- Loss of concentration.
- Low energy.
- Loss of enjoyment.
- Lack of interest in issues that would have normally been of interest.

- Feelings of hopelessness.
- Feeling that life is not worth living.
- Feeling suicidal and occasionally attempting to harm self.
- Feeling anxious and having physical symptoms of anxiety like shaking, palpitations, excessive sweating and dry mouth.
- Physical symptoms without a medical explanation.
- Feelings of guilt and worthlessness.
- Blaming self for the presence of depressive symptoms.
- Low self esteem.
- Feelings of being poor or in poverty.
- Feeling that part of their body or their whole body is not functioning properly.
- Feeling that they are being persecuted and that they deserve this persecution.

Depression may present with different symptoms in different ethnic groups. The vocabulary and language to express emotional feelings and the styles of expressing symptoms of depression vary across different cultures. Depressed mood and feelings of sadness are important in some cultures and physical symptoms, including pain, in other cultures. Physical symptoms may include fatigue, aches and pains, weakness, tiredness, sinking feelings in the stomach, attacks of hot and cold feelings, attacks of blushing, pains in the head, pains in the chest, pains in the stomach and gas in the abdomen. Older people of Caribbean origin rarely use the terms "sad" or "unhappy" to describe emotional distress, but they use other terms including "being low spirited", "fed up" and "weighed down". These descriptions of depressive symptoms are not exhaustive but give an indication of the broad range of depressive symptoms that may be reported by older people across different ethnic groups.

6. What should I do if there is concern about the possibility of mental disorders?

If you (or your carer) are concerned that you may have a mental disorder, then arrangements should be made to consult your general practitioner. For non-urgent situations an appointment with the general practitioner should be available within 48 hours. General practitioners are usually the first port of call for most individuals. General practitioners are also gate-keepers for referrals to specialist services, including specialist mental health services for older people.

7. What will the general practitioner do?

The general practitioner will be able to:

- Assess the older BME individual.
- Decide if the individual is suffering from a mental disorder.

In those with mental disorder, the general practitioner will have two options:

- Either to treat the individual within the general practice setting or
- Refer the individual to specialist mental health services for older people.

The choice of the more appropriate of these two options will be determined by:

- The skills, expertise and confidence of the general practitioner.
- The availability of suitable services for diagnosis and treatment within the general practice setting. For example, psychological therapies ("talking treatments") such as counselling may be available in some general practice settings.
- The severity of the mental disorder. Individuals with more severe mental disorders and potential risks (e.g. of self neglect or self harm) are more likely to be referred to specialist mental health services for older people.
- The difficulty in establishing a clear diagnosis. If there are difficulties in establishing the correct diagnosis then the individual may be referred to the specialist mental health service for older people.
- The difficulty in formulating a clear treatment plan. Individuals may be referred to specialist mental health services for older people so that specialists can facilitate an expert treatment plan.
- The availability of treatment in general practice settings. Some treatments, to start with, may only be available from specialist mental health services for older people. For example, new anti-dementia medications are generally only available in specialist mental health services for older people when the treatment is initially started.
- The need for specialist mental health services for older people to monitor response to treatments and side-effects of the treatment.
- There may be a requirement from national governmental policies and other national guidance that some treatments are administered by and the progress is monitored by specialist mental health services for older people. There may also be local policies in individual geographical areas requiring administration of some treatments and monitoring of progress for some mental disorders by specialist mental health services for older people.
- If the individual requires attendance at a day hospital or admission into hospital for further assessment and/or treatment then a referral to specialist mental health services for older people becomes necessary as the specialist services are gate-keepers to day hospitals and hospital beds.

The general practitioner may initiate some investigations

which may be similar to those described in Section 16 below. If the general practitioner decides to treat the illness, then the treatment may consist of one or more of the following:

- Correct any visual or hearing impairment.
- Medication.
- Counselling.
- Other psychological (“talking”) treatments (e.g. a treatment called cognitive behaviour therapy, when available, is often used to treat mild to moderate depressive illness).
- Referral to local social services for: attendance at a day centre to reduce loneliness or isolation; provision of carers to help with washing and dressing, housework, shopping, laundry and medication compliance; provision of meals on wheels; and, help with applying for appropriate social security benefits and allowances.
- Referral to specialists in medical care of older people (called geriatricians) if there is concern that medical illnesses may, at least in part, be responsible for the mental disorder.
- Referral to other services available in primary care including district nurses, dieticians, speech and language therapists, chiropodists, physiotherapists and occupational therapists, if it is felt that they may be able to improve the overall health of the older person and, in turn, their mental disorder also. The specific types of help some of these professionals can offer is described in Section 17 below.
- Referral to services provided by local voluntary sector organisations. For example, many local branches of Alzheimer’s Society provide patient and carer support groups for patients and carers with dementia. The voluntary sector organisations may include those for all older people or those for people from specific BME groups.

8. What are specialist mental health services for older people?

Most geographical areas will have a specialist mental health service for older people. Specialist mental health services for older people have been designed and developed to provide assessment and treatment for older people with mental health problems. Most such services include a multidisciplinary community mental health team, home visiting clinics, out-patient clinics (including specialist memory clinics), provision of assessment of older people with mental health problems on medical wards of the local general hospital (called a liaison service), day hospitals, and inpatients beds for admission for assessment and treatment, respite and long term care. Some services now also have home treatment teams where intensive

treatment can be provided in the patient’s home as an alternative to admission into hospital. Many specialist mental health services for older people are now integrated with local social services for older people.

9. What is the most likely first point of contact with the specialist mental health service for older people?

The first point of contact with specialist mental health services for older people is likely to be with the multidisciplinary community mental health team. There are two exceptions to this:

- If the situation is very urgent then the older person with possible mental disorder may be referred as an emergency to the local hospital’s accident and emergency department to consult the duty mental health team there.
- If the older person is already an inpatient on a medical ward in the local general hospital for a medical illness and may have a mental disorder, then s/he may be referred to the mental health team covering the medical hospital. Such teams are often referred to as liaison teams.

10. What is a multidisciplinary community mental health team?

The core members of a multidisciplinary community mental health team include junior and senior psychiatrists (psychiatrists are specialist doctors with expertise in the assessment and treatment of mental disorders), community psychiatric nurses, social workers, psychologists and occupational therapists. Other team members may include physiotherapists, speech and language therapists, dieticians, art therapists and chiropodists. All these professionals specialise in the treatment of mental disorders in older people and have specific skills. The core members of this team are usually likely to see newly referred patients first.

11. Which members of the multidisciplinary team will see me?

The multidisciplinary community mental team will decide which one member (or sometimes two members) of the team is most appropriate to see you first. This judgement will be based on the specific circumstances of your case. An effort is usually made to match the skills of the professional with your particular circumstances for the first assessment.

If you feel uncomfortable with a member of the

multidisciplinary community mental health team from the opposite gender assessing you or your culture and/or religion does not allow this, then you should ask for someone of the same gender as yourself.

12. Where will I be seen?

Most multidisciplinary community mental health teams plan to see newly referred older people at their home. There are many advantages for the first assessment to occur at the older person's home including:

- Older people may be frail and unable to easily travel to out-patient clinics.
- Avoiding the indignity of lengthy and time consuming journey to the hospital on hospital transport.
- Assessment at home allows the professional to see the home circumstances of the older person first hand. This may speed up the delivery of treatment and reduce the need for other assessments.
- It allows the professional easier access to the medication and contact details of any other professionals involved with the care of older person (e.g. district nurses).
- It also reduces the stigma attached to mental disorder that many older people may perceive to be very important.

13. As I do not speak English how will I communicate?

If you are not fluent in English or if you prefer to be assessed in your first language then one of the two scenarios should occur:

- You should either be assessed by a bilingual professional from the multidisciplinary community mental health team. However, this may not always be possible.
- Alternatively, you should be assessed with the help of a professional interpreter in your preferred language.

The exception to the above practice may occur in emergency situations when a bilingual professional or a professional interpreter may not be readily available. Should such a circumstance arise then the most readily available interpreter may be used including:

- Relatives.
- Non-clinical staff.

Ideally, use of relatives and other types of non-professional interpreters should be avoided. Reasons for this include:

- You may find it difficult to share sensitive information with a relative or a non-clinical staff member interpreting.
- Relatives and non-clinical staff usually lack the ability to translate what is said accurately.
- Relatives may give their version of events rather than yours.
- You may be concerned about the confidential information that you give the professional.

Although, in general, it is not appropriate for a relative to act an interpreter, it does not mean that you cannot ask your relative to stay with you during the assessment.

If you are not fluent in English or English is not your language you may find difficulty in answering some questions because there may not be appropriate vocabulary in your language for the question that is asked and there may not be appropriate vocabulary in English for the answer you give. This can make translation very difficult. If you feel this is happening you should ask the professional assessing you to repeat the question in a different way. It is possible that you may be able to answer the question appropriately if it is asked in a different way. If you do not understand a question ask the professional assessing you to ask the question in a different way.

14. How long will the assessment take?

Every assessment is different and time taken for an assessment can vary. Usually it may take anywhere between 45 minutes and two hours. Sometimes the professionals may need to come to see you again to complete the assessment.

15. What will they ask?

You will be asked a range of questions to complete what is called history taking and mental state examination. The range of areas covered during the assessment will include:

- Your symptoms.
- Detailed history of your symptoms.
- The nature and duration of your symptoms.
- The rate of decline of your symptoms.
- Your normal personality and memory function.
- Any symptoms of change in behaviour.
- Any symptoms related to your mood.
- Any symptoms which are unusual, for example, you may be hearing voices when there is nobody there.
- Any change in your personality.
- Any factors that may have contributed to the development of your symptoms.
- Any previous history of mental health problems.

- Any previous or current history of medical illnesses.
- Current medication history.
- Any visual or hearing impairment.
- Any history of mental health problems in the family.
- Relationships within the family.
- Any family conflicts and tensions.
- Your personal and social history.
- Who does the shopping, cooking and housework and if you are able to perform your personal care yourself.
- How long you have been in the United Kingdom.
- Reasons for migration to the United Kingdom.
- How you have adjusted and adapted to the environment in the UK.
- Your religion, ethnic and cultural background.
- Your fluency in English.
- Your literacy in your mother tongue.
- Your financial history.
- Whether you drink alcohol and how much.
- Whether you take other drugs and how much.
- Whether you smoke and how much.
- Whether you drive.
- What support is available from informal and family carers.
- What support you may already be receiving from social services.
- What support you may already be receiving from voluntary sector agencies including those in your own community.
- What support you already receive from your general practitioner and his/her surgery.
- Whether you have support from other people including friends.
- Whether you have had experience of racism.
- Whether you have had any contact with the police or the courts.
- What knowledge you have of available services from statutory and voluntary sectors and what your views about the suitability of these services are.
- Any special cultural and religious needs that you may have (e.g. dietary needs, need for interpreters for communication, need for specific religious facilities)
- You may be asked a series of questions which test your memory. Often this is done using a special form.

16. Will they speak to anyone else?

The professionals from the multidisciplinary community mental health team may wish to speak to your general practitioner and with any other professionals (e.g. social worker or a district nurse) who may already be involved in your care to find out more about your particular circumstances. With your permission the professional may also wish to speak to a member of your family and gather information on similar issues to the ones that you will have been asked about (as described in Section 15 above). The reason for doing this is that when people

have mental health problems they may not always be able to give accurate information about themselves. For example, an individual with memory problems may not be able to accurately recall the period of time for which they had memory difficulties, the nature of memory difficulties, whether the memory difficulties are deteriorating and the nature of any deterioration in memory difficulties. In such a circumstance additional information from someone who knows the person well would be invaluable in the overall assessment.

17. Will they do anything else?

Either at the initial assessment or when you are seen again, the psychiatrist (a doctor) on the multidisciplinary community mental health team may perform a physical examination. This doctor may examine various organs in your body. This examination will help identify:

- Any medical causes of the mental disorder. For example, an under active thyroid gland can result in depression and/or memory impairment.
- Any medical illnesses that may be contributing to your symptoms.
- Any medical illnesses that may influence future treatment of the mental disorder.
- Any visual or hearing loss. Correction of these deficits can improve the mental disorder.
- Any consequence of the mental disorder. For example neglect due to mental disorder may lead to dehydration, anaemia and malnutrition.

If you feel uncomfortable with a doctor from the opposite gender performing the physical examination or your culture and/or religion does not allow this, then you should ask for a doctor of the same gender as yourself.

They may also decide to perform a series of other tests (often called special investigations) including:

- Blood tests
- Examination of the urine
- Electrical tracing of the heart called an ECG
- Brain scan (usually one of two types is used: MRI or CT scans)

These tests may help:

- Establish the precise diagnosis.
- Identify risk factors for mental disorders (e.g. high blood pressure is a risk factor for developing a type of dementia called vascular dementia).
- Identify any consequence of the mental disorder due to neglect (e.g. dehydration, anaemia and vitamin deficiency).
- Identify any medical illnesses that may be complicating the mental disorder.

- Identify any abnormalities that may subsequently influence the treatment offered (e.g. abnormal liver function tests may be important if medication is considered for treatment).

Other forms of special investigations include:

- Psychological assessment including detailed memory tests. These memory tests may be needed to find out if you have memory problems, the extent of the memory problems and your strengths and weaknesses.
- Occupational therapy assessment to establish how you are functioning in your day to day life (e.g. can you wash and dress yourself, can you cook, can you do the housework and shopping) and whether you need any aids to help you (e.g. stair rails to facilitate climbing up the stairs).
- Speech and language therapy assessment for any difficulty you may have in your speech or if you have swallowing difficulties.
- Physiotherapy assessment to help improve your mobility and any pain you may have from medical illnesses like arthritis.

18. What is the purpose of these different assessments?

Some of the reasons for the different types of assessment were mentioned in Sections 16 and 17 above. The overall aim of any assessment is to:

- Establish the diagnosis of the precise mental disorder.
- Identify any risks to the older person with the mental disorder and to others.
- Identify the particular needs of the older person with the mental disorder.
- Formulate a treatment plan.

19. What treatments will I be offered?

You may be offered a range of treatments in a range of settings. The treatments you may be offered may include one or more of the following:

- Medications - You may be offered a medication from a group of medications called antidepressants if you have depression. You may be offered a medication from a group of medications called anti-dementia drugs if you have a dementia called Alzheimer's Disease. You may also be offered other types of medications depending on the specific circumstances of your case.
- Correction of any visual or hearing impairment.
- Treatment of any medical problems that may influence the mental disorder. This is usually done

by asking your general practitioner to help or by referring you to the specialist medical team for older people (often referred to as a geriatric team). The precise team treating your medical illness will depend on the urgency and nature of your medical problems.

- Treatment of specific physical and mental health problems by other members of the multidisciplinary community mental health team (e.g. dietician, physiotherapist, occupational therapist, and speech and language therapist - their roles were described in the last section) or referral to other members of the team in general practice (e.g. dietician, chiropodist, physiotherapist, district nurse and community matron). The precise choice of the professional you may be referred to will depend upon the urgency, availability and the precise nature of your symptoms.
- Psychological treatments ("talking treatment"). These include talking treatments referred to as counselling, cognitive behaviour therapy and psychotherapy. These may offered to you individually or in a group setting with other patients with similar problems.
- Social treatments – Social treatments include provision of carers for self care tasks, shopping, housework, laundry and compliance with medication, provision of meals on wheels, attendance at a day centre to reduce social isolation and to give your carer a break, befriender visiting you at home to help reduce social isolation, and help to apply for appropriate social security benefits. Most of these can be provided by a social worker who may also be part of the multidisciplinary community mental health team. Some of these can also be provided voluntary sector agencies.

You may be offered treatment in the following settings:

- A member of the multidisciplinary community mental health team may visit you at your home periodically. Some services also have a home treatment team whereby members of this team would be able to visit you at home several times a day and this is usually viewed as an alternative to admission into hospital.
- Attendance at an out-patient clinic. These clinics may be run by any member of the multidisciplinary community mental health team. They may be located at the hospital, at the site of community mental health team base in the community and in the general practitioners surgery. If you have memory problems you may be seen in specialist memory clinics.
- Attendance at a day hospital. You may be asked to attend a day hospital for further assessment and treatment if you require more intensive input than what can be provided in your own home or in the

out-patient clinic, but you are not so unwell that you require to be admitted into hospital. Some services may have separate day hospitals for those with memory problems (e.g. due to dementia) and those without memory problems (e.g. depression).

- Admission into hospital. You may require admission into hospital for further assessment and treatment. This would usually be on ward where there are other elderly patients. Some services may have separate wards for those with memory problems (e.g. due to dementia) and those without memory problems (e.g. depression). Also, nowadays services may also have single gender wards.
- You may be seen on a medical ward of the local general hospital where you may have been admitted if you have medical problems. The request for this assessment would usually be made by doctors and nurses looking after you on the medical ward.
- You may be seen in the accident and emergency unit of the local hospital if you need to be seen urgently for your mental disorder. This is particularly likely to occur at night or the weekends when many services, including the multidisciplinary community mental health team may not be operating.

20. What would happen if I refuse to accept an offer of admission into hospital?

The reasons for suggesting an admission into hospital should be explained to you. If these are not explained to you or you do not understand the reasons please do not hesitate to ask the member of the multidisciplinary community mental health team seeing you to explain the reasons for admission. If you decide to decline the offer of an admission then this professional will usually try and see if the further assessment and treatment can be provided in an alternative setting including in the day hospital or with the home treatment team at your home. However, not all services will have a day hospital or a home treatment team.

If it is considered that you require admission and there are risks to either yourself or others and you decline the offer of the admission, then the member of the multidisciplinary community mental health team seeing you may need to consider an assessment under the Mental Health Act. If this path is chosen then you will be assessed by two doctors (at least one of them would have special expertise in mental health issues) and an approved mental health professional (they may be social workers, nurses, psychologists and occupational therapists with special expertise in mental health issues). If all three agree that you fulfil the specific criteria for detention in hospital under the Mental Health Act then you will be admitted to hospital under the Mental Health Act. This path would normally only be followed after careful discussion

with you and your carer and after all other options are carefully considered. If you are admitted into hospital under the Mental Health Act then you would usually be informed of your rights under the Mental Health Act and also be given an information leaflet explaining your rights to you.

If you do not object to the admission into hospital but you are judged, by the member of the multidisciplinary community mental health team, to lack the capacity to make the decision to agree to being admitted into hospital, then an assessment under the Deprivation of Liberty Safeguards of the Mental Capacity Act may be requested. You could then be admitted under the Deprivation of Liberty Safeguards into hospital. This is designed to protect you when you lack the capacity to make the decision to agree to being admitted into hospital.

21. What would happen if I am admitted into hospital?

Once you are admitted into hospital you would usually be seen by a nurse and by a doctor. They will further assess you and are likely to ask you similar questions to those that you may have been asked by a member of the multidisciplinary community mental health team prior to the admission. The doctor will perform a physical examination of your different organ systems. The doctor may also arrange for you to have blood tests and other tests similar to those described in Section 17 above. The nursing staff will monitor your blood pressure, pulse rate, breathing rate, temperature, weight, food and fluid intake, sleep and bowel habits. Doctors and nurses will regularly talk to you to establish the following:

- How you are feeling.
- Assess improvement in your symptoms.
- Provide information on strategies to improve your symptoms.
- Monitor the side effects of medication.
- Share with you the findings of the various tests that may have been done.
- Arrange other forms of care and treatment.
- With your permission they may also speak to your relatives to ascertain more information and share the treatment you would be receiving.
- Discuss with you the areas of help you feel you need.

Other professionals who may work on the wards include social workers, occupational therapists, psychologists, physiotherapists, dieticians, chiropodist and speech and language therapists. One or more of these professionals may see you and this would depend upon your particular individual circumstances.

22. What would happen if I am admitted to the day hospital?

Exactly the same procedure as described for admission into hospital in Section 21 above would be followed if you were admitted to the day hospital. The main difference would be that you would come to the day hospital only during the day. Day hospitals in most services provide transport for travel between home and the day hospital, although if you are able to travel independently then you may be able to do so.

23. What would happen if I am followed-up at home?

If a decision is made for you to be followed-up at home, then an appropriate member of the multidisciplinary community mental health team will come to see you at home. Depending on your circumstances periodically other members of the multidisciplinary community mental health team may also come and see you at home. They will:

- Discuss with how you are feeling.
- Assess any improvement in your symptoms.
- Assess any side-effects if you have been prescribed medication.
- Coordinate all aspects of the treatment plan for you. This may involve ensuring that other professionals asked to see you have seen you and find out what the outcome of these additional assessments are and what care they may have offered you.
- Some patients may need to receive injections periodically for their mental disorder and this would normally be administered by the community psychiatric nurse.
- Discuss with you areas of help you feel you need.

24. What would happen if I am followed-up in the out-patient clinic?

You may be seen by any member of the multidisciplinary community mental health team in the out-patient clinic. Traditionally, most clinics were conducted by doctors, but this is now changing. The out-patient clinic may be located at the hospital, on the premises of the community mental health team and in the general practitioner's clinic. You may also be seen in a specialist memory clinic if you have memory problems. The type of the clinic, the location of the clinic and the precise member of the multidisciplinary community mental health team seeing you will depend upon your circumstances and the types of services that are locally available.

The following may occur when you are seen in the out-patient clinic:

- Discuss with how you are feeling.
- Assess any improvement in your symptoms.
- Assess any side-effects if you have been prescribed medication.
- Co-ordinate all aspects of the treatment plan for you. This may involve ensuring that other professionals asked to see you have actually seen you and find out what the outcome of these additional assessments are and what care they may have offered you.
- You may be asked to have further blood tests if you are on some medications and this would be explained to you. These tests may be done at the clinic or you may be asked to go to the hospital to have them done, and this will depend on how this is done locally in your area.
- Discuss with you what areas of help you feel you need.

25. Would somebody be able to be present with me?

Either at the initial assessment or during subsequent follow-up assessments you would be able to have a relative or a friend or a trusted person with you when you are seen.

26. Can anyone else help me and support me?

There are groups of people called advocates. In different services they may be employed in different ways and by different agencies. Advocates would usually talk to you and advocate on your behalf. They can express your views and concerns to the professionals involved in your care on your behalf. You have a right to have access to advocates. If the professional that you have contact with does not mention advocates to you, you should ask for more information on this important source of support.

A new type of advocate, the Independent Mental Capacity Advocate, has been introduced through the Mental Capacity Act 2005. These advocates will usually only be involved in your welfare if:

- You lack the capacity to make a decision and
- There is no one else (like a relative or friend or a carer) available to support you and
- The decision involves serious medical treatment or placement into a residential or nursing home or hospital for a long period.

27. All this is complex! Will anyone co-ordinate my care?

Most services use a model where one professional involved in your care will be designated to be

responsible for co-ordinating all aspects of your treatment and care. They may have different names in different services and their names include:

- Care co-ordinator.
- Care manager
- Case manager
- Key worker

Irrespective of the name, such an identified professional should be responsible for co-ordinating all aspects of your treatment and care for the mental disorder. This professional should also be the point of contact for you should you have any concerns and you would normally be given the name and telephone number of that professional.

28. Will I be given written information?

You may be given several types of written information:

- The professionals you see may give you general information about their service.
- You may be given written information about some of the treatments you may receive or are already receiving. For example, you may be given written information about medication.
- You should be given written information about your personal treatment and care plan. In most services regular meetings will be called to review your treatment and care plan. Everyone involved in your care, including yourself, your relatives, your friends and/or your carers (with your agreement) will be invited to this meeting. The treatment and care plan agreed at this meeting should be written up and a copy given to you.
- Also, any letters written about you (e.g. to general practitioners) usually should be copied to you.

If you are not given written information about the service, about your treatment or about your care plan, then you should ask for the relevant information. Written information may or may not be made available to you in your preferred language. This may depend upon the local circumstances of your service. If you are given written information in English and this information is not available in your preferred language, then you should ask the professional co-ordinating your care to help you read the information with the help of an interpreter.

Information on videos and DVDs may also be available and this is considered later below in Appendix 2.

29. Would I be able to see a traditional healer or a faith healer?

You may have already seen a traditional healer or a faith healer before you see a member of the multidisciplinary community mental health team. You may decide to see a traditional healer or a faith healer at the same time as you see a member of the multidisciplinary community mental health team or after seeing the latter.

There should be no objection to you seeing both a member of the multidisciplinary community mental health team and a traditional healer or a faith healer. However, it is important that the member of the multidisciplinary community mental health team or the traditional healer or the faith healer seeing you is made unequivocally aware that you are consulting the other party. This is important from the viewpoint of the multidisciplinary community mental health team because the member of the multidisciplinary community mental health team may wish to:

- Discuss your case with the traditional healer or the faith healer to improve the overall care you receive.
- Identify any potential side-effects and interactions with other medications or any traditional medications you may be prescribed.
- Establish the importance of any cultural and religious factors that the traditional healer or the faith healer may be better informed about.
- Ensure that your entire treatment package is carefully co-ordinated if you wish to receive both types of treatment together.

Traditional healers or faith healers may wish to seek similar information from the member of the multidisciplinary community mental health team seeing you.

30. Will my language, cultural and religious needs be met?

Each professional involved in your care and each component of the old age psychiatry service should endeavour to meet your language, cultural and religious needs.

The use of professional interpreters for individuals who lack fluency in English or prefer to communicate in their first language was discussed in Section 13 above for new assessment. Essentially the same rules apply whenever you are seen by a professional in healthcare and social care settings. Also, if you are given any written information in English and if you are unable to read this information then please ask the professional giving you the information to arrange an interpreter to read and translate the information to you.

All mental health services are required to ensure that their staff members have received training pertaining to cultural sensitivity, awareness and competence. The professionals assessing you would normally endeavour to gather information about your cultural and religious requirements from you and your relatives. They would also endeavour to meet any identified cultural and religious requirements irrespective of the setting you are treated in. If you feel that your cultural and religious needs will not be met or are not being met then do not hesitate to immediately inform the professionals looking after you. It may be that the professionals may have been unaware of your particular cultural and religious needs. In such circumstances you should clearly explain your particular requirements to the professionals. These may include:

- The professionals assessing you should consider your language, cultural and religious needs in the assessment and in the formulation of your treatment and care plan. If you feel that they are misinterpreting your symptoms which may be related to your language, culture or religion you should discuss this with the professionals concerned.
- Special dietary requirements (e.g. halal food or vegetarian food).
- Wearing cultural or religious clothes.
- Possessing religious artefacts. If possession of some religious artefacts is not permitted then this should be carefully discussed by the professional with you and you should be given clear and sound clinical reasons for any prohibition.
- Availability of prayer facilities, access to religious leaders of the patient's faith and freedom to practice religious activities.
- Separation between men and women in some ethnic groups, where this is traditional practice, should be respected.
- Cultural or religious factors that may prohibit certain treatments.
- The professional conducting the assessment and providing the treatment may need to be from the same gender as the patient for some groups particularly when sensitive issues are discussed or when physical examination is conducted.
- Interpreters should be available and used for communication purposes when the patient is not fluent in English or if the patient's preferred language for communication is not English.
- Any professional giving written information should ensure that the patient can read and understand this information. Otherwise arrangements should be made for an interpreter to read and translate the information to the patient.

The above list only contains a few examples and this is not exhaustive. Even if your particular language, cultural and religious needs are different to those given

above, you should unequivocally raise them with the professionals at the earliest opportunity. There is no reason why the professionals involved in your care and the providers of the service should not make strenuous efforts to give serious consideration to your language, cultural and religious needs.

31. Are there other sources of information?

A list of some national agencies which can provide helpful information to you and your carer on a range of issues are given in Appendix 1.

A list of videos and DVDs that you and your carer may find helpful are also listed in Appendix 2 along with some other useful information.

In your local area, the specialist mental health service itself, social services and voluntary sector organisations (including those for your ethnic group) may have additional resources and information on mental disorders and local service provision. Such information from statutory services may or may not be available in your preferred language and you may need to ask the professional looking after you to arrange an interpreter to read and translate any written materials.

32. What can I do if I have concerns?

If you have any concerns about your illness and your treatment and care plan then you should initially discuss this with the professionals involved in your care. You may wish to use the help of an advocate for this purpose. Advocates were described in detail in Section 26 above.

If, after the above discussion with the professionals involved in your care, you are still concerned then you can access the Patient Advisory and Liaison Service for the mental health service for older people. Again you can seek the help of an advocate to facilitate this. The Patient Advisory and Liaison Service can be helpful in helping you resolve your concerns.

If your concerns continue to persist despite the above two steps then you may wish to complain formally to the complaints department of the mental health service for older people. The professionals involved in your care should be able to provide you with information on contacting the complaints department. Again you can seek the help of an advocate to facilitate this.

33. How long will I remain a patient in the mental health services?

It is difficult to give a precise indication of the duration

of time you would spend as a patient in the mental health service for older people because many factors may influence this duration including:

- Type of mental disorder you may have.
- Severity of the mental disorder you may have.
- Response to treatment.
- History of recurrence of the mental disorder.
- Need for treatments that can only be provided by specialist mental health services for older people on an ongoing basis.
- Nature, quality and quantity of support that you are receiving or may receive from family, friends, social services and the voluntary sector.

34. What can I do to prevent mental disorder?

Prevention of mental disorders should be seen at three levels:

- Prevention of mental disorders before they occur in the first instance.
- Early identification of mental disorders and early intervention with treatment to prevent further deterioration and amelioration of the symptoms.
- Once the mental disorder is well established to treat it rigorously to prevent any long term disability and handicap resulting from the mental disorder.

A series of factors may contribute to these three levels of prevention:

- Healthy eating.
- Exercise.
- Keeping your mind active.
- No to smoking.
- To drink alcohol in moderation.
- To avoid illicit drugs.
- Risk factors for dementia, particularly vascular dementia, include high blood pressure, heart disease, strokes, diabetes and high blood levels of cholesterol. These disorders are common in some BME groups, including those of Indian subcontinent and African Caribbean origins. You should ensure that you are regularly checked by your general practitioner or the general practice nurse on an ongoing basis for these risk factors after the age of 45 years. Early identification and treatment of these risk factors may later reduce the risk of developing dementia, and if identified after the onset of dementia then the rate of decline may be slowed down. Many general practices now run programmes for identifying such risk factors. Also, your general practitioner is required to offer you annual physical and mental examination if you are aged 75 years and over.
- Take steps to reduce social isolation. This may

- include joining social clubs, luncheon clubs, attending day centres run by social services or by voluntary sector, attending adult educational courses and doing voluntary work. This may help avoid developing depression or expedite recovery from depression and prevent relapse because social isolation is an important risk factor for depression.
- If you have been recently bereaved and you are finding it difficult to adjust to the bereavement then you may wish to seek help from bereavement counselling. Different types of bereavement counselling services may be available in different geographical areas and your general practitioner should be able to provide more information. Such counselling may help avoid the development of depression.
- If you have financial difficulties then you should seek early help from social services and department of works and pensions as you may be entitled to a range of benefits that you have not claimed. This may help avoid developing depression or expedite recovery from depression and prevent relapse because financial difficulties are an important risk factor for depression.
- If you have hearing or eyesight problems then you should consult your general practitioner and see if they can be improved. Hearing and visual deficits are risk factors for mental disorder in old age.
- If you are physically unwell you should seek early advice from your general practitioner as physical illness is also an important risk factor for mental disorder in old age, particularly depression. Also, some physical illnesses may actually cause symptoms similar to mental disorders (e.g. an under active thyroid gland can cause memory impairment, depression and delusions).
- You should have your medication regularly reviewed by your general practitioner and/or the pharmacist because some medications have side-effects which can lead to mental disorders and interaction between different medications can do the same.
- If you are concerned that you have a mental disorder then you should immediately see your general practitioner.
- If you are treated by your general practitioner or by the specialist mental health service for older people then you should carefully consider accepting their advice on your treatment and care and continue the treatment until you are advised to stop it. This will expedite recovery and reduce the risk of relapse.
- If you are recommended by your general practitioner, social worker or the mental health service for older people to receive additional help from carers for self care, shopping, housework and compliance with medication, consider accepting this carefully. Such help can reduce any effect of disability that you may have because of mental disorder.
- If you feel you are being physically, emotionally or

financially abused by anyone then you should immediately seek help from your general practitioner, from a social worker, from any other professional you may be receiving care from, or from the police. Such abuse can be a risk factor for developing mental disorders. Also, those who have mental disorders are at particular risk of such abuse which in turn may lead to decline in the mental disorder.

- The National Institute of Health and Clinical Excellence recently introduced guidance on the mental well-being and older people through four key recommendations: occupational therapy; physical activity, walking schemes and training (www.nice.org.uk/nicemedia/pdf/PH16QuickRefGuide.pdf). A variety of professionals and service components have been nominated to implement this guidance. Interestingly, it unequivocally states that if resources are limited then they should focus on the most disadvantaged older people, including those from BME groups.

36. APPENDIX 1: Useful contacts

PRIAE has produced ground breaking work in mental health under its CNEOPSA Project (Care Needs of Ethnic Older People suffering from Alzheimers) including a film to raise awareness and understanding among elders and professionals as well as policy makers:

- Managing Dementia Care to Black and Minority Ethnic Elders in the UK, Denmark, France (1998) by Naina Patel, Naheed Mirza et al., Russell Housing Press
- Dementia Matters Ethnic Concerns –a film and guide on dementia and minority ethnic elders covering the UK, Netherlands, Spain and Finland (1999) PRIAE

To obtain copies see www.priae.org or write to info@priae.org

Your local Black and minority ethnic age organisation

In many areas of the UK, community organisations that specialise in age services may also be able to give or direct to specific information and services concerning mental health. These are critical organisations supporting BME elders from different ethnic groups. You can find these organisations from your local directory and/or contact adult social services who should be able to give you a list. Such organisations have been engaged with PRIAE producing work in mental health and other areas.

Age Concern provides free advice and information on health, housing, money, transport and day care to older people and their family/friends. It provides local services such as lunch clubs, day centres and transport.

Telephone: **0800 009966**

Address: Astral House, 1268 London Rd, London SE16 4ER

Email: infodep@ace.org.uk

Website: www.ageconcern.org.uk

Alzheimer Concern Ealing (ACE) provides various services for people with dementia living in West London. It offers support and respite to relieve the stress experienced by people with dementia and their carers. The organisation and its staff were referred to in the PRIAE study as key players in information and service developments in dementia care to local black and minority ethnic elders.

Telephone: **020 85684448**

Address: 223 Windmill Road, London W5 4DJ

Email: alzconcern@btconnect.com

Website: www.alzheimersconcern.co.uk

Alzheimer's Society provides information and support for those with any form of dementia and their carers. Local groups can provide home visits and information about different types of dementia and about local services and support.

Helpline: **0845 300 0336**

Address: Gordon House, 10 Greencoat Place, London SW1P 1PH

Email: info@alzheimers.org.uk

Website: www.alzheimers.org.uk

Mind offers help on a range of mental health issues and works to make mental health services more responsive to the needs of black and minority ethnic communities.

Helpline: **0845 766 0163**

Address: PO Box 277, Manchester M60 3XN

Email: info@mind.org.uk

Website: www.mind.org.uk

Touchstone offers services that transform the lives of people experiencing mental health difficulties.

Telephone: **(0113) 271 8277**

Address: 2-4 Middleton Crescent, Beeston, Leeds LS11 6JU

Parkinson's Disease Society offers advice, information and support to anyone affected by Parkinson's, and helps with managing the condition as well as planning ahead.

Call Free: **0808 800 0303**

Address: PDS Helpline, Parkinson's Disease Society, 215 Vauxhall Bridge Road, London SW1V 1EJ.

Email: enquiries@parkinsons.org.uk

Samaritans provides a daily twenty-four hour service, giving help and support to persons suffering from distress, despair, depression and suicidal thoughts.
Helpline: **08457 90 90 90 (UK)**
or **1850 60 90 90 (ROI)**
Address: Chris, PO Box 90 90, Stirling FK8 2SA
Email: jo@samaritans.org

Depression Alliance offers information (including newsletters, booklets and leaflets) on depression as well as treatment options. DA also maintains a national network of self help groups for people experiencing depression.
Telephone: **0845 123 2320**
Email: information@depressionalliance.org
Website: www.depressionalliance.org

Equip is a support group that offers help and support to people suffering from stress, anxiety and depression.
Helpline: **01622 717656**
Address: London Road, Aylesford, Kent ME20 7NQ
Email: stressadvisor@lycos.com
Website: <http://stresshelp.tripod.com>

Carers Gateway provides support for carers in work and training, information about services, carers' groups and organisations, and social events.
Telephone: **01484 226050**
Address: Kirklees Carers Gateway, 1st Floor, 2 Market Street, Huddersfield HD1 2EH
Email: carers.gateway@kirklees.gov.uk
Website: www.kirklees.gov.uk/carers

Citizens Advice Bureau (over 3,000 locations) offers free face-to-face advice in their various bureaux, but also in GP surgeries, in hospitals, in colleges, prisons and courts. Most bureaux also offer home visits and some provide email advice. You can find their local number in your telephone directory or visit them on www.adviceguide.org.uk.

NHS Direct offers help and advice 24 hours a day. Trained nurses will tell you what steps to take next.
Telephone: **0845 46 47**

Department of Works and Pensions provides information on the following points:

- Attendance Allowance
- Income Support
- Financial Assessment
- Benefit Entitlements

You can find their local number in your telephone directory.

Social Services will carry out a needs assessment for your particular situation. You can find their local number in your telephone directory.

Language Services: There are 12 free telephone numbers that you can call for the most commonly spoken languages in the UK:

0808 800 0130 Arabic
0808 800 0131 Bengali
0808 800 0132 Cantonese
0808 800 0133 French
0808 800 0134 Greek
0808 800 0135 Gujarati
0808 800 0136 Hindi
0808 800 0137 Polish
0808 800 0138 Punjabi
0808 800 0139 Turkish
0808 800 0140 Urdu
0808 800 0141 Vietnamese

37. APPENDIX 2: Helpful videos and DVDs and other sources of information

Policy Research Institute for Ageing and Ethnicity (www.priae.org) developed an excellent film, available as a DVD, **Dementia Matters Ethnic Concerns**, which was aimed at BME elders, professionals and policy makers to raise awareness and set the context for key issues to address in BME dementia care. Alzheimer's Concern Ealing (telephone number **0208 568 4448**) have developed an excellent educational video in Punjabi for carers and dementia-sufferers. Alzheimer's Society (telephone number **01904 633581**) have developed an excellent educational video for African Caribbean dementia-sufferers and their carers. Alzheimer's Society have also recently developed a DVD for carers and dementia-sufferers, based on fictional story with commentary from professionals, in several south Asian languages including Hindi, Urdu and Gujarati.

Care Services Improvement Partnership's (CSIP) Older People's Mental Health Programme (www.olderpeoplementalhealth.csip.org.uk/mental-health-and-well-being-of-black-and-minority-ethnic-elders/showcase-event-presentations.html) is currently running a one year national project to promote the mental health and well-being of BME elders and to improve their access to mental health services. This includes national mapping of resources and projects for BME elders, and details of these are available on its website. This includes an educational film on depression for the Bangladeshi group on depression, a DVD raising awareness of depression and promoting actions to achieve a "healthy mind and healthy body" for the Chinese group, and resource packs and leaflets for depression for other BME groups, including those for Irish traveller and Roma Gypsy groups.

PART 3

Guide to Mental Health Assessment

Preface

PRIAE has been working tirelessly over the last decade or so to raise awareness of mental health problems in BME elders. PRIAE has worked with BME elders and carers, organisations that represent BME elders and carers and with various professional groups to raise awareness, improve access to services and develop services which are culturally sensitive, aware and competent. PRIAE has led on a range of research and development projects in this area particularly its 'ground breaking' work under its European initiative, CNEOPSA (Care Needs of Ethnic Older People with Alzheimer's) Project begun in 1997. This produced a study followed by a first European film which the then Minister of Health called 'impressive and authoritative'.

PRIAE has collaborated with ISCRI to deliver together the work related to PRIAE project, *Managing better mental health care for black and minority ethnic elders*. There is a paucity of guidance for clinicians relating to the assessment and management of mental health problems in BME elders. This guide is written with the aim of supporting such staff and others involved in mental health care.

Acknowledgements

This guide was commissioned by PRIAE as a result of listening to the many voices of professionals attending PRIAE events in mental health and/or PRIAE staff attending mental health events during the past few years. One message consistently heard from clinicians and related staff in mental health was that an assessment guide geared to working with minority ethnic elders would aid them in their work.

We hope that this guide will contribute to the implementation of work for better mental health for all elders particularly at a time when mental health with older people is given a policy focus. Professor Ajit Shah has written this guide as an experienced clinician working in a multicultural setting for the PRIAE project taking in comments of all the participants of the CNEOPSA working group who met at the PRIAE workshop, especially Dr Geetha Oommen and other colleagues in the West London Mental Health NHS Trust.

We hope that you will use this guide and encourage others to refer to it. We welcome your comments to send to info@priae.org or ajit.shah@wlmht.nhs.uk

Professor Naina Patel OBE
Founder and Executive Director of PRIAE

A. INTRODUCTION

Mental Health Assessment

Black and minority ethnic (BME) elders with mental disorders may experience difficulties that can be explained by a model of multiple jeopardy, and their clinical assessment should consider these disadvantages. Contributory factors to this model include ageism, racism, gender disparities, restricted access to health and welfare services, internal ethnic divisions and class struggle (Boneham, 1989; Rait et al., 1996).

In the United Kingdom (UK), formal assessment of patients with possible mental disorders are usually initially conducted by the general practitioner and subsequently by specialist old age psychiatry services; specialist old age psychiatry services for BME elders are at an early stage of development. The clinical assessment of BME elders with mental disorders should be seen in the context of planning and development of specialist services for them.

B. Planning and Development of Mental Health Services

The planning and development of mental health services for BME elders requires information on the definition of BME elders, population demography, epidemiology of mental disorders, and the availability and utility of existing mental health services (Shah & Ellanchenny, 2002).

B. 1. Definition of BME elders.

Any definition of BME elders should account for both ethnicity and age. The age cut-off in most UK old age psychiatry services is 65 years (Shah & Bhatkal, 2005); the same cut-off age should be applied to BME elders to avoid confusion and fragmentation of services, and to facilitate clear delineation of resources (Shah & Ellanchenny, 2002).

The terms race, culture and ethnicity are often erroneously used interchangeably. Race is a phenomenological description based on physical appearance (Bhopal, 1997). Culture describes features that are shared and which bind individuals together. The definition and identification of ethnicity is problematic (Mckenzie & Crowcroft, 1996) because it includes aspects of race and culture, and other characteristics including traditions, language, religion, upbringing, nationality and ancestral place of origin (Rait & Burns, 1997). The definition of BME groups used in the governmental document *Delivering Race Equality in Mental Health Care* (Department of Health, 2005) was "... all people of minority ethnic status in England. It does not only refer to skin colour but to people of all groups who may experience discrimination and disadvantage, such as those of Irish origin, those of Mediterranean origin and East European migrants". A useful definition of BME individuals is "those with a cultural heritage distinct from the majority population" (Manthorpe & Hettiaratchy, 1993). Thus, BME elders comprise a heterogeneous group with unique individual and collective experiences (Manthorpe & Hettiaratchy, 1993). Hence, for the purpose of service provision all BME groups should not be amalgamated and specific consideration should be given to individual BME groups.

B. 2. Demography

Service planning requires data on the size, age distribution and projected population trends. The proportion of elderly from BME groups in England and Wales has progressively increased from 1% in the 1981 population census (Office of Population Census

and Survey (OPCS), 1983) to 3% in the 1991 population census (OPCS, 1993) to 8.2% in the 2001 population census (Shah et al., 2005a; 2007a). Overall, 531,909 (7.1%) of all older adults in England and Wales were from BME groups in the 2001 population census (Shah, 2007a). The five most prevalent BME elderly groups are the Irish (24.9%), other white (10.4%), Black Caribbean (10.6%) and Indian (6.6%) groups (Shah, 2007a).

B. 3. Epidemiology

A community study of Indian sub-continent origin elders in Bradford reported a prevalence rate for dementia of 7% (Bhatnagar & Frank, 1997). A community study of elderly Gujaratis in Leicester reported prevalence rates of 0% and 20% in the 65-74 years and 75+ years age groups respectively (Lindesay et al., 1997a); the stability of the diagnosis of dementia in this study was confirmed at 27-month follow-up by a Gujarati psychiatrist (Shah et al., 1998). A community study in Liverpool reported the prevalence of dementia in individuals of Black African, Black Caribbean, Black other, Chinese and Asian origin as 8%, 8%, 2%, 5% and 9% respectively (McCraeken et al., 1997). A community study in Islington reported the prevalence of dementia in those born in the UK, Ireland, Cyprus, and Africa or the Caribbean as 10%, 3.6%, 11.3% and 17% respectively (Livingston et al., 2001).

The Bradford study reported prevalence rates for depression and anxiety as 20% and 2% respectively (Bhatnagar & Frank, 1997). The Liverpool study reported prevalence rates for depression in those of Black African, Black Caribbean, Chinese and Asian origin of 19%, 16%, 13% and 15% respectively (McCraeken et al., 1997); these figures were comparable to those in indigenous elders. The Islington study reported prevalence rates of depression in those born in the UK, Ireland, Cyprus and Africa and the Caribbean of 18%, 16.5%, 28% and 14% respectively (Livingston et al., 2001). The Leicester study reported prevalence rates of 22%, 1% and 4% for agoraphobia, simple phobia and panic attacks respectively in elderly Gujaratis; simple phobias were less prevalent in the Gujaratis than the indigenous population (Lindesay et al., 1997b). Although the prevalence of depression was not measured in the Leicester study, the depression severity scores were not different in Gujarati and indigenous elders.

The prevalence of depression in convenience samples of elderly Bengalis and Somalis in east London was higher than the indigenous white British group (Silveira & Ebrahim, 1995, 1998a,b), but lower in a convenience sample of elderly Gujaratis in north London (Ebrahim et al., 1991; Silveira & Ebrahim, 1998a,b). Although

there are no population-based studies of late onset schizophrenia, one study reported an increased rate of new contacts with services among African Caribbean elders compared to the indigenous elders (Reeves et al., 2001).

Collectively, these studies suggest that the prevalence of dementia and depression, the two most common mental disorders in old age, among BME elderly groups is either similar or higher than in the indigenous white British group.

B. 4. Implications of demographic changes

The prevalence of dementia doubles every 5.1 years after the age of 60 years (Jorm et al., 1987; Hofman et al., 1991) and the prevalence of depression in the elderly is about 15% (Shah, 1992a). Thus, with the increase in the BME elderly population, the absolute number of cases of dementia and depression in BME elderly groups will also increase, with a consequent increase in demand for mental health services (Shah & Ellanchenny, 2002). One recent study estimated the absolute number of cases of dementia in the BME population to be 11,860 in the UK in 2004 (Kings College London & London School of Economics, 2007). Another study estimated the absolute number of cases of dementia between 7270 and 10786 and of depression between 33559 and 52980 among BME elders from all groups combined (Shah, 2008).

B. 5. Current services and their utility

Information on the availability and utility of existing service provision can help to identify gaps in the current service provision and methods of improving services, including integrating new service developments with existing services. Limited local and national data on the utility of existing secondary health care services, social services and voluntary sector services by BME elders suggests poor uptake (Barker, 1984; Spence & Atherton, 1991; Manthorpe & Hettiarachy, 1993; Lindesay et al., 1997b; Shah & Dighe-Deo, 1997; Jagger, 1998). Data on ethnicity are now routinely collected by all trusts and social services departments and these should be available to service planners.

B. 6. Pathways into care

General practitioners (GPs) generally act as gate-keepers for secondary care services. Pathways into care encompass the following stages: first appearance of illness in the community; consultation with the GP; identification and management of the illness by the GP; referral to secondary care; and, identification and

management of the illness in secondary care (Goldberg & Huxley, 1991). There may be several reasons for the observed discrepancy between the prevalence of mental disorders being similar to or higher in BME elders than in indigenous white British elders, high general practice consultation rates by BME elders and poor representation of BME elders in secondary care old age psychiatry services.

B. 6.1. The effect of patient and family factors on primary care consultations

BME elders (Marwaha & Livingston, 2002; Lawrence et al., 2006a; Bowes & Wilkinson, 2003; Purandare et al., 2007) and their family members (Manthorpe & Hettiarachy, 1993; Rait & Burns, 1997; Adamson, 2001) may be unaware or not recognise symptoms of mental disorder, and may dismiss them as a function of old age. This may be exaggerated if patients are unable to communicate their symptoms due to absence of appropriate vocabulary or inability to speak English (George & Young, 1991; Shah, 1992b, 1997a,b, 1999; Wai Yin Chinese Women Society, 2007). Moreover, family members and patients may believe that little can be done, be unaware of existing services and application procedures, have had poor experience of existing services, and feel that existing services are inadequate, inaccessible and culturally insensitive (Bhalia & Blakemore, 1981; Barker, 1984; Age Concern/ Help the Aged Housing Trust, 1984; McCallum, 1990; Hopkins & Bahl, 1993; Lindesay et al., 1997b; Bowes & Wilkinson, 2003). They may also fear the stigma attached to mental illness (Barker, 1984; Manthorpe & Hettiarachy, 1993; Livingston et al., 2002; Marwaha & Livingston, 2002; Wai Yin Chinese Women Society, 2007), and may consult traditional healers (Bhatnagar, 1997), seek spiritual help (Marwaha & Livingston 2002; Lawrence et al., 2006b) and seek help from the family (Lawrence et al., 2006b) rather than consult GPs for their mental disorder.

B. 6.2. The effect of GP factors on consultations

Routine GP consultations may not identify mental disorders in BME elders due to several reasons (Shah et al., 2005b). First, the prevalence of mental disorders in those consulting GPs may be low; some possible reasons for this were discussed in the section on patient and family factors above. Mental health primary care consultation for mental health was low in elderly Indians, Pakistanis, Bangladeshis and Chinese (Gill et al., 2007). African Caribbean elders, compared to white British elders, in Islington were more likely to chose not to consult their GP or psychiatric services (Marwaha & Livingston 2002). African Caribbean and

South Asian elders with treated and untreated depression expressed a willingness and desire to talk about psychological problems, but felt there was insufficient time to do this with their general practitioner (Lawrence et al., 2006b). However, the reason for primary care consultation for mental health in Caribbean and African elders was high (Gill et al., 2007) suggesting that other factors may contribute to low prevalence of BME elders in secondary care. Second, mental disorder in those consulting GPs may be less severe. Third, symptoms of mental disorder, including behavioural and psychological symptoms of dementia, which often precipitates clinical presentation, may be less frequent, less severe or different in BME elders consulting GPs than in indigenous elders (Haider & Shah, 2004; Shah, 2007b). Fourth, data on the clinical presentation, diagnostic features and natural history for mental disorders in BME elders are sparse (Patel et al., 1998; Patel, 2000; Shah, 2007b), and individual GPs may see relatively few BME elders with mental disorders. Therefore, GPs may lack clinical experience, expertise and diagnostic skills needed for BME elders, even psychiatrists experience this difficulty (Lindesay, 1998; Shah, 1999, 2007b). Fifth, these difficulties may be exaggerated by language and communication difficulties (Patel, 2000; Lindesay, 1998). Sixth, there is a paucity of screening and diagnostic instruments for mental disorders in BME elders (Shah et al., 2005b; Shah & Mackenzie, 2007). Seventh, bias and prejudice of clinicians may also complicate consultations (Solomon, 1992). Finally, well-intentioned family members may withhold information if they feel that it will present the patient in a "bad light" (Shah, 1997a, b, 1999).

Even if mental disorder is identified, it may or may not be treated. It may not be treated because the GP believes that nothing can be done, believes ethnically sensitive secondary care services are not available, may be unaware of procedures for accessing secondary care services, and may have had previous experience of poor response from secondary care (Shah et al., 2005b). If the mental disorder presenting to the GP is less severe or lacks troublesome behavioural and psychological symptoms of dementia, the GP may consider referral to secondary care unnecessary (Shah et al., 2005b). The GP may feel that s/he can communicate with the patient better, particularly if they have the same ethnic background as the patient; up to 70% of Asians in the UK are registered with Asian GPs (Johnson et al., 1983). Also, the GP may wish to refer the patient to secondary care but the patient and/or the family may be reluctant due to the reasons discussed in the section on patient and family factors above (Shah et al., 2005b).

B. 6.3. Factors in secondary care that may influence diagnosis and management of mental disorders

There is a paucity of studies examining BME elders with mental disorders in old age psychiatry services. Almost all the concerns discussed in relation to primary care apply to secondary care. There are only three published studies of old age psychiatry service users in local areas (Redlinghuys & Shah, 1997; Odutoye & Shah, 1999; Bhatkal & Shah, 2004) and these services may have been particularly accessible to BME elders due to local service development factors. Additionally, the 2007 "Count Me In" census of all psychiatric inpatients, including those over the age of 65 years, in England and Wales (Commission for Healthcare Audit and Inspection, 2007) reported on admission rates for BME elders. The admission rate, compared to that for the total elderly population of England and Wales, for those aged 65 years and older from different ethnic groups was: higher in the white Irish, other white, white and Black Caribbean, other Asian, Black Caribbean, Black African and other black groups; lower in the white British and Chinese groups; and, there was no difference with the standard population in the white and Black African, white and Asian, Indian, Pakistani and Bangladeshi groups.

B6. 4. Other services

BME elders and their carers are often unaware of and under-use community services including meals on wheels, home help, community nurses, incontinence advisors, health visitors, physiotherapists, occupational therapists, chiropodists and day centres (Bhalia & Blakemore, 1981; Atkins et al., 1989; McCallum, 1990; Lindesay et al., 1997b; Patel et al., 1998).

C. Mental Health Service

Components for BME Elders: An Assessment Journey

Services for BME elders with mental disorders should be integrated with existing ethnocentric services to avoid fragmentation and inability to compete for scarce funding (Blakemore, 1985; Patel & Mirza, 2001; Ong, 2001).

C. 1. Sources of new referrals

Medical personnel, non-medical personnel and lay people may wish to make referrals (Banerjee, 1998; Challis et al., 2002). The advantages and disadvantages of a medical or an open referral system are described elsewhere (Shah & Ames, 1994; Shah & Bhatkal, 2005). An open referral policy should be preferred for BME elders because it is likely to improve access to mental health services for this vulnerable group (Shah & Ellanchenny, 2002).

C. 2. Mode of referral and service hours

Referral methods include postal letters, faxed letters, e-mailed letters and telephoned referrals. The National Service Framework for Older People (Department of Health, 2001) requires development of a referral protocol from primary care and a single assessment process, and this will standardise the method of referral and the information required from the referrer. Ideally, referrals should be assessed within a few days. Other service innovations including evening or weekend service, albeit expensive, could particularly improve service access for BME elders.

C. 3. Site of the initial assessment

Initial assessment should ideally occur in the patient's home (Challis et al., 2002); the exception being liaison referrals for in-patients in general hospitals. The advantages of home assessments listed in Table 1 (page 50) are amplified for BME elders because of difficulties in concluding assessments (Shah & Ellanchenny, 2002). Moreover, cultural factors relevant to the assessment can be observed first hand at the home visit.

C. 4. Nature of the initial assessment

The multidisciplinary old age psychiatry team should comprise of psychiatrists, psychologists, community

psychiatric nurses, occupational therapists and social workers (Shah & Ames, 1994; Shah & Bhatkal, 2005); other disciplines like physiotherapists, speech therapists, dieticians and chiropodists should be available to support this core team. The multidisciplinary team should review referrals and allocate two most appropriate disciplines to assess the patient, although poorly resourced services may lack the luxury of sparing two staff members for one assessment. Where possible one team member should either speak the patient's language and/or, at least, be familiar with the patient's culture; this will allow better understanding of the patient and facilitate reduction in barriers to accessing services (Shah & Ellanchenny, 2002).

The outcome of the initial assessment should be discussed with the multidisciplinary team in a formal meeting to facilitate liaison between team members, allow discussion of the clinical management and allow cross-referrals between team members. Each patient should subsequently be managed using the principles of Care Programme Approach or Care Management, whereby care co-ordinators provide assistance from their discipline and co-ordinates the wider management package. The patient, carer, referrer, GP and other interested parties should be kept fully informed of progress at all stages. This can be conducted under the Care Programme Approach or the Single Assessment Process whereby a formal written care plan is issued to all interested parties. This is particularly important for BME elders as they have difficulty in accessing services. There may be a need either for the care plan to be written in the patient's language (the author is unaware of any services using this approach) or for the use of interpretation services to ensure that the patient and the carer understand and agree to the care plan.

C. 5. Diagnostic issues

Mental disorder is difficult to diagnose in BME elders (George & Young, 1991; Patel & Mirza, 2000a) because of issues listed in Table 2 (page 50). Also, there is a paucity of diagnostic instruments for dementia and depression, the two most common mental disorders in old age, for use in this group (Shah, 1998).

Cognitive tests developed in one ethnic group may not be appropriate for another ethnic group because they are influenced by culture, education, language, literacy and numeracy skills, sensory impairment, unfamiliarity with test situations and anxiety (Shah et al., 2005b). Instruments screening for cognitive impairment developed for English-speaking indigenous population have been developed in several BME languages, and the Mini-Mental State Examinations (Folstein et al., 1975) developed in several BME languages are listed in Table 3 (page 51). The abbreviated Mental Test Score (Quereshi

& Hodkinson, 1974) has also been developed in several Asian languages for use among Indians, Pakistanis and Bangladeshis and in English for use in African Caribbeans (Rait et al., 1997; 2000a,b).

Depression and other emotional disorders may present with different clinical features in different BME groups (Abas, 1996; Abas et al., 1996, 1998; Lindsay, 1998; Shah, 1999; Livingston & Sembhi, 2003). Emotional expression, including depression, in different cultures is influenced by several overlapping concepts including the context of disclosure, vocabulary and language of emotional expression, selective expression of emotions and definition of self (Lindsay, 1998). Gender, age, family relationship, professional status and religious background can influence the disclosure of distress (Lindsay, 1998) and some examples are illustrated. The vocabulary and language to express emotions across cultures is variable (Abas, 1996; Abas et al., 1996, 1998; Lindsay, 1998; Shah, 1999).

Equivalent vocabulary to express emotions in different languages may not be present (Lindsay, 1998). Furthermore, styles of expressing biological and physical symptoms of emotional disorders including anxiety and depression may be different in different cultures (Abas, 1996; Abas et al., 1996, 1998; Lindsay, 1998). Depressed mood and feelings of sadness are prevalent in some cultures and somatic symptoms and pain in other cultures (Lindsay, 1998; Lindsay et al., 1997b; Livingston et al., 2002). Semi-rural Indian subcontinent origin elders may not regard depression and anxiety as mental illnesses and may perceive them as bodily illnesses with symptoms like fatigue, aches and pains, weakness, tiredness and other physical symptoms (Bhatnagar, 1997); they may consult doctors with physical symptoms or consult traditional healers like Hakims and Vaidis, the latter having no boundary between physical and psychological scenarios (Bhatnagar, 1997). Somatic symptoms including sinking feelings in the stomach, attacks of hot and cold feelings, attacks of blushing, pains in the head, pains in the chest and pains in the stomach were more common among UK Gujarati elders than indigenous elders in a population-based study (Lindsay et al., 1997b). The possibility of depression should be considered if Indian sub-continent elders present with persistent low energy, bodily aches and pains, and gas in the abdomen (Bhatnagar, 1997). Among elderly depressed Cypriots in London somatic symptoms are more prevalent than in indigenous elders (Livingston et al., 2002). However, somatic symptoms should be seen in parallel with, rather than an alternative to, expression of distress (Lindsay, 1998). Older African Caribbeans in the UK rarely use the terms "sad" or "unhappy" to describe emotional distress (Baker et al., 1995; Abas, 1996; Abas et al., 1996, 1998), but they use other terms including "being low spirited", "fed up" and "weighed down" (Abas, 1996; Abas et al., 1996, 1998).

The 15-item Geriatric Depression Scale (GDS) (Sheikh & Yesavage, 1986), Brief Assessment Schedule Cards (Adshead et al., 1992) and the Caribbean Culture-specific Screen (CCSS) (Abas et al., 1998) have been successfully evaluated for use with UK African Caribbeans. The CCSS was developed a priori by ascertaining terminology used by African Caribbean elders to describe emotional distress. The Symptoms of Anxiety and Depression Scale was developed for use with Gujarati, Somali and Bengali elders in London (Ebrahim et al., 1991; Silveria & Ebrahim, 1991, 1998a, 1998b).

Table 4 (page 51) lists some basic rules for administering cognitive tests to BME elders. However, these screening instruments have been developed in the subject's language and because translated versions of instruments generally have questions in the subject's language, the clinician cannot directly administer the instrument unless s/he is fluent in the relevant language. Other more cumbersome instruments have been developed for use in research and would not be appropriate for routine clinical practice. There are no assessment instruments measuring behavioural and psychological symptoms of dementia (non-cognitive symptoms) in BME dementia-sufferers.

C. 6. Communication

Many BME elders do not speak English and a significant proportion are illiterate in their mother tongue (Barker, 1984; Manthorpe & Hettiarachy, 1993; Lindsay et al., 1997b). This has important implications not only for assessment but also for communication of information about treatment and available services. Communication difficulties can be minimised if the clinician is fluent in the patient's language (Ong, 1991). However, bilingual clinicians are uncommon (Phelan & Parkman, 1995), but appreciated when available (Redelinghuys & Shah, 1997; Hoxey et al., 1999). Relatives and friends, non-clinical staff, clinical staff and professional interpreters have been used for interpretation (Phelan & Parkman, 1995; Shah, 1997a,b). Lay interpreters lack formal training, may translate their opinion in either direction and may be emotionally biased, and patients may be reluctant to share confidential sensitive information with lay interpreters (Phelan & Parkman, 1995; Shah & Mackenzie, 2007). In view of this, the use of professional interpreters has been advocated, particularly at key events including assessments, reviews, case-conferences and discussion with carers (Centre for Ethnicity and Health, University of Central Lancashire, Mental Health Act Commission and National Institute for Mental Health England, 2003; Department of Health, 2004, 2005). Sadly, the availability and utility of professional interpretation services is patchy. Each service needs to identify the

common BME languages in their area and develop a local professional interpretation service in those languages, preferably by providing specialist training in mental health (including dementia) for the professional interpreters. For illiterate patients and carers, audio-tapes, video-tapes and diagrammatic representations giving information on management and service-related issues may also be helpful (Lindesay et al., 1997b; Shah & Ellanchenny, 2002).

The interpreter should be given adequate warning of the interview, details of the venue, details of the patient's gender, precise ethnicity, language and dialect, and the nature, purpose and likely duration of the interview. The reasons for using the interpreter, and the nature, purpose and likely duration of the interview should also be explained to the patient. Ideally, the same interpreter should be used for serial interviews. Useful tips for clinicians in using interpreters are described elsewhere (Phelan & Parkman, 1995).

C. 7. Gathering collateral history

Carefully gathered collateral history from other informants like relatives and friends provides invaluable information (Shah et al., 1998; Shah, 1999). However, there are pitfalls: well intentioned family members and friends may withhold information if they fear this will lead to the patient being seen in a "bad light" (Shah, 1997a,b, 1999); and, they may fear being accused of failing in their duty of care.

C. 8. Site of follow-up

Following the initial assessment, some patients may not require further follow-up and advice to the referrer may suffice. Further follow-up should be for specified and well-defined reasons including further assessment, treatment, rehabilitation, monitoring of drug and other treatments and side-effects, monitoring of mental state, support for patients and carers, and advocacy (Shah & Ames, 1994; Shah & Bhatkal, 2005). Patients can be followed up at hospital-based or primary care-based out-patient clinics, specialist memory clinics and home visiting clinics, and these can be offered by any multidisciplinary team member (Shah & Bhatkal, 2005). Ideally, these clinics should be located close to clusters of BME elders.

C. 9. Day hospitals

Day hospitals are an important component of mental health services with different models including separate dementia and functional day hospitals, a single central day hospital or several smaller day hospitals closer to

BME population clusters, and travelling day hospitals (Hettiarachy, 1985; Tym, 1991; Hoxey et al., 1999). They provide assessment, treatment, rehabilitation, short and medium term support, development of networks and initial support for carers (Shah & Bhatkal, 2005). They allow the patient to remain at home whilst receiving treatment. They may be particularly important for BME elders who may have anxiety about inpatient units being unable to meet their cultural needs.

C. 10. Transportation

Elderly patients usually need provision for transportation to hospital-based facilities because of poor mobility, sensory impairment, physical illness and cognitive impairment (Shah & Ellanchenny, 2002). Additionally, BME elders may be unable to use public transport because of language and communication difficulties and for fear of racial harrasment (Barker, 1984; Shah & Ellanchenny, 2002).

C. 11. Inpatient care

There are three types of admissions: assessment and treatment; respite; and, continuing care. The indications and objectives for admission are well described elsewhere (Shah & Ames, 1994; Shah & Bhatkal, 2005). BME elders and their carers may be reluctant to accept inpatient admission because of stigma, poor insight, belief that the illness is a function of old age and will not improve or spontaneously improve, psychological defence mechanism of denial, and fear that the inpatient environment may not be culturally appropriate (Shah & Ellanchenny, 2002). These attitudes will be amplified if the ward environment, equipment and staff are not culturally sensitive and the patient experiences communication difficulties due to language barriers.

C. 12. Social services

Management of patients at home requires provision of social support (Reddy & Pitt, 1993), which is often provided by family, friends and neighbours (Victor, 1991). Formal support includes availability of social workers, home carers for personal care, housework and shopping, meals on wheels, day centres and befriending schemes (Victor, 1991). These services should be be culturally sensitive (e.g. availability of vegetarian meals on wheels), otherwise BME elders poor perception of services will be reinforced.

C. 13. Liaison service

A liaison old age psychiatry service should be available to departments of geriatric medicine, the rest of the general hospital, residential facilities for the elderly, social services and voluntary sector day facilities, home care providers, voluntary sector organisations, and other local government services (Shah & Bhatkal, 2005). A range of multidisciplinary staff can provide this service.

Some local authorities have developed specialist day centres and residential homes for BME elders (Blakemore, 1985, Patel 1990), and other such services are emerging. BME elders prefer such facilities because they are able to meet others from the same background and communication is not an issue. Staff in such facilities should receive training in the identification and management of mental disorders. Mental health services for BME elders should also develop close ties with voluntary sector agencies both for the general population and those that are specifically for BME groups. Many BME groups have their own community organisations, which may provide a range of services; BME elders are more likely to accept these services because the staff members are more likely to belong to their own communities. Liaison with such organisations will allow mental health service providers to learn more about BME cultures (McCallum, 1990). Development of "satellite models" of specialist developments in selected ethnic minority organisations has been suggested (Patel & Mirza, 2001). These agencies could also act as advocates, offer advice on available services, and develop interpretation services for BME elders. There is also a case for outreach workers to be employed either by the statutory services or voluntary sector services or both to disseminate information on mental health services to whole BME communities (Spence & Atherton, 1991).

Liaison links should also be developed with practitioners of traditional medicine. Although, there are no data on the use of these by BME individuals with mental disorders, anecdotally this is not an uncommon practice. Professionals should be aware of relevant aspects of traditional medicine because patients may present late because doctors are perceived to be unhelpful, patients may present with an interpretation rather than symptoms and traditional remedies may produce side-effects and interactions (Bhopal, 1996a,b).

All BME recipients of liaison services should receive information on the range of services provided by the local mental health service, the mechanics of making a referral, and the types of clinical issues that could be referred (Patel & Mirza, 2001; Shah & Ellanchenny, 2002).

C. 14. Carer issues

Mental health services should play an important role in carer education, but often this is provided by voluntary sector agencies like the Alzheimer's Society. Local partnerships between mental health services, social services and voluntary sector organisations should be utilised to develop a programme of carer education. Although the profile of BME carers is similar to indigenous carers (McCallum, 1990), because many BME elders live in extended family households, it is often erroneously assumed that the family provides care and services are not needed (Boneham, 1989; McCallum, 1990; Redelinghuys & Shah, 1997; Odutoye & Shah, 1999). Therefore, the traditional role of mental health services for carer education, carer support, provision of basic care, respite and other back-up services is amplified for BME elders with mental disorders.

C. 15. Staffing level and composition

BME staff members are generally under-represented in all community services (Atkins et al., 1989), and staff members are often unfamiliar with cultural issues (Bhalia & Blakemore, 1981). The service can be made culturally more sensitive by employing more BME staff reflecting the population of the area served (Ong, 2001; Patel & Mirza, 2001; Department of Health, 2005) and raising awareness of cultural issues among staff (Shah & Ellanchenny, 2002; Department of Health, 2001, 2005). Specialist BME workers can also help improve clinical practice (Patel & Mirza, 2000a; Patel et al., 1998), and successful examples have been described (Hoxey et al., 1999). Moreover, clinical and non-clinical staff from BME background can facilitate integration, acceptability and accessibility of services, improved communication, cultural sensitivity, informal and formal training of other staff on cultural issues, development of links with local BME organisations and advocacy (Shah & Ellanchenny, 2002). Appropriate staffing composition and adequate environmental milieu of the service allows integration of specialist old age psychiatry services for BME elders with ethnocentric services (Ong, 2001; Patel & Mirza, 2001).

C. 16. Equipment, design and cultural sensitivity of facilities

All equipment needed for ethnocentric services is also needed for BME elders, and are described elsewhere (Shah & Bhatkal, 2005). The service settings, staff and equipment should be culturally sensitive (Shah & Ellanchenny, 2002). Careful attention should be paid to cultural practices of gender segregation (elderly Indian men and women may chose not to mix in

public), bathing strategies, food (availability of appropriate food like halal meat), adequate prayer and washing facilities, access to chaplains of different religious denominations, signs and notices in BME languages (and diagrams for illiterate patients), reality orientation cues in BME languages and relevant reminiscence groups (Atkins et al., 1989; Patel & Mirza, 2001; Shah & Ellanchenny, 2002).

Any literature given to indigenous patients should be available in BME languages, and when this is not the case translation services should be used (Patel & Mirza, 2001; Shah & Ellanchenny, 2002). The Mental Health Act Commission and some voluntary sector agencies like Alzheimer's Society have literature in various BME languages. However, for illiterate BME elders, the contents of these documents should be read and explained with the help of a translator (Shah & Ellanchenny, 2002). The use of audio and video tapes and diagrammatic representation can also be helpful (Lindesay et al., 1997b). Alzheimer's Concern Ealing has made a video in Punjabi for carers of dementia-sufferers. PRAIE has produced a film which provides an analysis of the issues and makes recommendations to policy-makers, researchers, professionals in health and social care, BME families and carers, and other organisations (Patel & Mirza, 2000b).

C. 17. Quality assurance and audit

The activities of the overall dementia service and the individual disciplines pertaining to BME elders should be subject to internal and external audit and quality assurance monitoring to identify flaws and areas of good practice. The latter can be strengthened and the former improved; if necessary the audit findings can be used to argue a case for increased resources (Shah & Ellanchenny, 2002). Findings of internal or external audit should be carefully communicated to all staff, including budget holders, and should be closely linked to a formal mechanism of change. Principles of integrated care pathways and variance tracking to identify problematic areas should be utilised and this is likely to be particularly helpful for BME groups.

C. 18. Education

Training in better recognition of mental disorders has been advocated by professionals as an important need when dealing with BME elders (Patel et al., 1998; Patel & Mirza, 2000a). Old age psychiatry services should be involved in education including education on cultural aspects of mental disorders for multidisciplinary staff in such services, geriatricians, GPs, social service staff and voluntary sector staff. Development of training materials and their dissemination to BME communities to improve awareness has also been suggested (Patel & Mitrza, 2000a). Furthermore, local services should play an important role in public education at a local level and this should involve BME elders, their carers and voluntary sector BME agencies. National public education campaigns should be implemented locally with the perspective of BME subjects in mind.

D. The Actual Process of Assessment

The actual process of assessment for BME elders with mental disorders should be seen in the context of individual components of the old age psychiatry service and the models of planning and developing services for them. The aims of assessing any individual with possible mental disorder are to establish the diagnosis of mental disorder, identify the needs of the patient and the carer, identify current or potential risks, and develop care plans. Care plans should be developed for treatment, for further management, to meet the identified needs of the patient and the carer, and to undermine the risks. This basic assessment process for BME elders with mental disorder should essentially be the same as for indigenous elders, although careful consideration should be given to cultural factors (Patel & Mirza, 2001). The basic aims of the assessment may be achieved after one or several meetings with the patient and carer, a period of community or out-patient follow-up, and inpatient or day hospital admission; this will depend upon the complexity of the clinical issues, severity of illness, perceived risks, and available support in the community from family, statutory services and voluntary sector services.

Due to many complex issues discussed in earlier sections, it may be necessary to assess BME elders serially on several occasions before concluding the assessment. Although serial assessments are time consuming and a drain on resources, they allow accurate diagnostic and management conclusions for BME patients who have difficulty in accessing services and where there are communication and diagnostic difficulties. Serial assessment over time may also clarify diagnosis of mental disorder, and may be of particular value in dementia because cognitive impairment in dementia declines over time (Shah et al., 1998) – the author has been caught out in a few cases where an incorrect diagnosis of dementia was initially made, but at follow-up the patients had successfully responded to trials of antidepressants because the correct diagnosis was depression.

D. 1. Individual components of the assessment

The process of assessment should follow the conventional principles of history taking, from the patient, collateral history gathering from other informants like relatives, mental state examination, physical examination and special investigations. All this information should be gathered in a culturally sensitive manner and be under-pinned by the safeguards

described in earlier sections. A professional interpreter (unless the clinician is bilingual) should be used throughout the assessment process when English is not the patient's or the carer's first language to improve the accuracy of the assessment. The basic rules for use of interpreters described earlier should be followed.

D. 2. History gathering

A direct history from the patient and a collateral history from an informant (like relatives) should be gathered; collateral history is vital (e.g. because the diagnosis of dementia requires longitudinal evidence of cognitive and functional decline, which the dementia-sufferer may be unable to provide). Table 5 (page 53) illustrates the generic and culturally-relevant components of history gathering.

D. 3. Mental state examination

Mental state examination is the cornerstone of good psychiatric practice and vital in identifying evidence of pathological psychiatric phenomena including cognitive impairment. The method of mental state examination for BME subjects should be identical to that for indigenous subjects, but cultural factors must be considered. Mental state examination is particularly difficult with the aid of an interpreter and should be conducted patiently and slowly, and the patient should be given adequate opportunity to respond to questions. Sometimes, due to difficulties in interpretation, it may be necessary to repeat the same question in different formats before securing a reliable response. Furthermore, it may be necessary to assess the mental state on several occasions to ensure consistency and completeness. Cognitive tests are influenced by education, literacy and numeracy skills, lack of awareness of western culture (tests are generally biased towards western concepts) and unfamiliarity with test situations; as BME patients are particularly vulnerable to these factors, careful attention should be paid to their cognitive assessment. Bilingual clinicians could use the MMSE (Table 3) (page 51) and the AMTS, both described in earlier sections, for screening of cognitive impairment in the relevant BME group. However, these screening instruments have been developed in the subject's language and because translated versions of instruments generally have questions in the subject's language, the clinician cannot directly administer the instrument unless s/he is fluent in the relevant language.

D. 4. Physical examination

Detailed physical examination will identify aetiological factors contributing to mental disorders (e.g.

hypothyroidism, strokes, cardiovascular diseases etc. may contribute to dementia or depression), medical illnesses contributing to the clinical presentation, medical illnesses likely to complicate future treatment, sensory impairment (hearing and visual impairment), sequelae of neglect due to mental disorder (e.g. dehydration, anaemia and malnutrition etc.). It should be conducted in an identical manner to that for indigenous elders, but cultural factors must be respected. For example, in some cultural groups it may be important for the doctor conducting the physical examination to be of the same gender as the patient (e.g. Indians). During physical examination, an interpreter of the same gender as the patient may be helpful to accurately communicate with the patient. Some sensitive aspects of physical examination (like rectal examination to exclude constipation – a common cause of agitation in dementia-sufferers) may need to be deferred until the clinician is satisfied that a good relationship has been developed with the patient; otherwise there is a risk that the patient may disengage from the assessment, leading to an incomplete and possibly inaccurate assessment.

D. 5. Special investigations

Special investigations (Table 6) are undertaken to help establish the precise diagnosis, identify risk factors for mental disorders, identify any sequelae of mental disorder due to neglect (e.g. dehydration, anaemia vitamin deficiency etc.), identify any inter-current medical illnesses complicating mental disorder, and identify any abnormalities that may subsequently compromise medical treatment (e.g. abnormal liver function tests may be important if psychotropic drugs are considered for treatment). The patient and the carer, through a professional interpreter, if English is not their first language, should be given a detailed explanation of the actual investigations, the indications for them, and the findings in a culturally sensitive manner. Other forms of special investigations include psychological assessment with neuropsychometry, occupational therapy assessment, speech and language therapy assessment and physiotherapy assessment. These should be conducted in an identical manner to that for indigenous patients, but with careful consideration of cultural factors. Neuropsychometric assessment may be needed to evaluate cognitive impairment to aid the diagnosis of dementia and to identify strengths and weaknesses. Sadly, most of the neuropsychometric tests used by psychologists have not been formally evaluated for use among BME groups. This does not mean that these tests should not be used with BME patients, but the findings should be interpreted cautiously because they are influenced by education, literacy, numeracy and cultural factors.

D. 6. Bringing together all the information

Findings from the history, collateral history, mental state examination, physical examination and special investigations should be reviewed with the multidisciplinary team before reaching conclusions on the diagnosis and other aspects of the assessment. This patient and the carers should be accurately informed of issues related to mental disorders and their care plans and they should be given an adequate opportunity to ask any questions – all with a professional interpreter if their first language is not English. They should be given verbal and written information on how to access services identified in their care plan and also that pertaining to advocacy services (Patel & Mirza, 2001; Shah & Ellanchenny, 2002). Although, ideally, written care plans should be provided in the patient's mother tongue, the author is unaware of any services where this occurs, and usually interpreters are used to explain the care plan. For illiterate patients, the care plan could be provided on an audio-tape in their language, but the author is unaware of any services using this approach.

D. 7. Additional support for the assessment

There may be many difficulties in successfully completing the assessment of BME elders with mental disorders. Clinicians may feel a need for additional advice. This may be available locally from other clinicians with knowledge of the relevant culture, and the Royal College of Psychiatrists keeps a register of psychiatrists with expertise in specified BME groups. Additional help in this manner may prove an invaluable tool in the assessment of BME elders with mental disorder.

E. References

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Table 1: Advantages of assessing BME elders at home

1. Home consultations rate approaches 100% (Benbow, 1990; Shah, 1994; Anderson & Aquilina, 2002).
2. Home environment is observed first hand (Benbow, 1990; Banerjee, 1998; Anderson & Aquilina, 2002).
3. Avoidance of unnecessary occupational therapy and social work assessments ordered from the outpatient clinic (Shah, 1994).
4. Easier access to family members and other informants like neighbours (Benbow, 1990; Banerjee, 1998).
5. Easier access to log books kept at the patient's home by home carer, home help and district nurses for collateral history (Shah & Bhatkal, 2005).
6. Easier access to medication and assessment of polypharmacy, poor compliance, drug interactions, dependence on benzodiazepines and hoarding for overdose (Shah & Ames, 1994; Banerjee, 1998).
7. Avoidance of stigma of attending a psychiatric clinic.
8. Avoidance of the indignity of lengthy ambulance rides, irregularities in the timing and availability of ambulance and related modes of transport.
9. Avoidance of personal costs of any trip to the clinic incurred patients or their families (Benbow, 1990; Shah & Ames, 1994)
10. Older patients with hearing and visual deficits, cognitive impairment, reduced mobility and physical illness and disability, and linguistic difficulties may not be able to travel to the clinic (Banerjee, 1998)

Table 2: Cultural factors influencing the diagnosis of mental disorders in old age

1. Communication difficulties (George & Younger, 1991; Shah, 1992, 1997a,b, Patel et al., 1998; Livingston & Sembhi, 2003).
2. Taboo topics (Shah, 1992).
3. Stigma attached to mental disorder (Livingston et al., 2002; Marwaha & Livingston; Wai Yin Chinese Women Society, 2007).
4. Bias and prejudice of clinicians (Solomon, 1992).
5. Institutional racism (Solomon, 1992).
6. Unfamiliarity of symptoms of mental disorder by relatives (Manthorpe & Hettiarachy, 1993).
7. Illness seen as a function of old age by family.

**Table 3:
MMSE in languages other
than English**

Chinese
Korean
Finnish
Italian
Yoruba
Spanish
Thai
Cree
Hindi (Rait et al., 2000a)*
Punjabi (Rait et al., 2000a)*
Urdu (Rait et al., 2000a)*
Bengali (Rait et al., 2000a)*
Gujarati (Rait et al., 2000a; Lindesay et al., 1997a)*
Malyalum
Sinhalese

* Developed for BME subjects speaking the specified language and living in the UK. Only the relevant reference for those MMSEs is given. Interested readers may wish to get the actual scales from the authors directly because of copyrights issues. These screening instruments have been developed in the subject's language and because translated versions of instruments generally have questions in the subject's language, the clinician cannot directly administer the instrument unless s/he is fluent in the relevant language. Thus, bilingual clinicians could use the MMSE for screening of cognitive impairment in the relevant BME group, but English-speaking clinicians are likely to find difficulty in using them.

**Table 4:
Basic rules for administering
cognitive and other tests to
BME elders**

1. Correction of sensory impairment (Lindesay, 1998).
2. Explain carefully the nature, purpose and duration of the test.
3. Ensure the instructions are explicit and simple.
4. An un-scored trial run may be needed to ensure the subject has understood the purpose of the test (Chandra et al., 1994).
5. Assessor should use a calm, patient and reassuring approach.
6. Assessment should occur in the patient's mother tongue (Shah, 1992, 1999).

Table 5: History from the patient and collateral history from other informants

- *Presenting complaint
- *History of presenting complaint
- *Rate, nature and duration of cognitive impairment.
- *Premorbid cognition
- *Behaviour disturbance
- *Affective symptoms
- *Psychotic symptoms
- *Personality change
- *Any dangerous behaviour (e.g wandering)
- *Past psychiatric history
- *Past and current medical history
- *Medication history
- *Sensory impairment
- *Family history
- **Family relationships
- **Family conflicts and tensions
- *Personal and social history
- **Duration in the UK
- **Reasons for migration
- **Adjustment in the UK
- **Degree of acculturation
- **Religion and ethnic background
- **Fluency in English
- **Literacy in mother tongue
- *Financial history
- *Presence of appointeeship, power of attorney and court of protection receivership
- *Alcohol and substance misuse history
- *Driving history (dementia-sufferers are required to inform the DVLA of the diagnosis)
- *Available support for informal and family carers
- *Available support from social services
- *Available support from voluntary sector
- *Available support from primary care
- **Availability of friends
- **Experience of racism
- *Forensic history
- *Premorbid personality
- *Knowledge of available services from statutory and voluntary sectors
- *Their views about potential services
- **Any special cultural needs (e.g. vegetarian food)

* Generic item.

** Items with special significance for BME subjects

Table 6: Special investigations

A. Usually indicated

1. Blood Tests: FBC
U/E
CRP
ESR
LFT
TFT
Calcium
B12
Folate
Glucose
Lipid profile
Syphilis serology
2. Urine: Culture and sensitivity
3. Cardiology: ECG
4. Radiology
Chest X-ray
MRI Brain Scan (CT if this not available)

B. Sometimes indicated

1. Lumbar puncture
2. Formal neuropsychometry
3. Occupational therapy
4. Nursing assessment
5. Social work assessment
6. Speech and language therapy assessment
7. Physiotherapy assessment
8. Dietetic assessment

PART 4

Examples of Good Practice in the Provision of Mental Health Care for BME Elders

Preface

The importance of minority ethnic organisations has been stated clearly in all of PRIAE's work. They are considered as 'critical players' in responding to BME elders' ordinary needs and in turn are involved in developments that the Institute generates. One of ISCRI's flagship developments is 'community engagement'. This section highlights good practice examples that BME elders' identified at seminars organised by ISCRI.

This section is written with the aim of informing what good practice exists and how mental health policies and strategies (dementia strategy for example) could support these organisations and others involved in mental health care.

Acknowledgements

This section on good practice brings together a variety of developments and experiences of organisations who have developed mental health work for BME elders. This is a specialist area and one that presents several challenges both from elders and communities as well as mainstream care providers and professionals.

Nicole Crompton has written this piece following BME elders' identification of 'good practice' following their participation at PRIAE-ISCRI events. We thank all the elders, staff and volunteers involved in this work. What they do to support BME elders is a huge achievement in its own right: to establish services in mental health to BME elders is complex, challenging and rewarding. We hope that you will find this section useful and support such organisations working to improve mental health care.

We welcome your comments to send to info@priae.org or ncrompton@uclan.ac.uk

Professor Naina Patel OBE
Founder and Executive Director of PRIAE

1. Better Mental Health Care for BME Elders: Selected Case Studies

In this section areas of good practice in the mental health care of BME elders have been identified with the use of real practice example case studies. During a series of conferences and seminars organised for BME elders in London, Birmingham and Manchester elders were asked to identify examples of what they thought were good practice; these were recorded in an interim report for this project.

These examples of good practice were then followed up with preliminary phone calls during which additional information was gathered. During this process it was discovered that many of the examples highlighted had been time limited projects which had since completed and staff had moved on making their inclusion impractical.

From the remaining examples several organisations were approached with a request to host a visit from a member of staff from PRIAE/ISCRI and a BME elder with a view to gathering further information to assess the organisations suitability for inclusion as a case study identifying good practice in mental health care for BME elders. Several of those approached were reluctant to contribute but from those that were a sample was chosen that reflected a geographic spread and a range of different types of initiative. As work continued other examples of good practice were suggested and these were pursued.

Visits were made to organisations throughout the country; where possible a BME elder accompanied a member of PRIAE/ISCRI staff on visits. However this did not happen on every visit. Often this was due to not having a BME contact from the area visited; on other occasions the health of the elder or the person they cared for compromised their contribution.

All those organisations that contributed to the case studies were given the opportunity to review them and check for factual correctness.

In the following sections you will find case studies thematically split. The decision was made to thematically divide case studies as reports of some type of good practice were repeated regularly thus these are grouped to showcase different approaches.

Thus you will see organisations appearing in several sections. Details of the organisations which contributed to this section can be found in Appendix A.

2. Attracting BME Elders

2.1. Communities which are traditionally thought harder to reach

During the process of collecting information for these case studies some communities were mentioned as being difficult to access and thus support. Several reasons for the difficulty accessing these communities were identified:

- Newly settled communities without any established community organisations by which to access them – Somali Community of Birmingham, some eastern European or refugee communities.
- Traditional beliefs surrounding mental health preventing access to services – Chinese community of Leeds, Manchester and Birmingham, various South Asian communities, Gypsy community of Derbyshire
- Reluctance to engage with any statutory services – Gypsy community of Derbyshire
- Services which do not or are not perceived to meet their needs - Gypsy community of Derbyshire, South Asian community of Bradford

Addressing these barriers is key to attracting people into services and throughout the case studies we see various ways in which organisations are doing this.

Leeds Older People's and Disabled People's Strategic Partnership and Service Development Team found having a community development worker (CDW) dedicated to development work with BME elders improved access to mental health services by smaller or harder to reach minority communities. The success of this post was evident in the evolving ethnic breakdown of the dementia register. A dedicated CDW was made possible for 2 years in Leeds by funding received from Partnership with Older People (POPS) funding. Having work with older people added on as an additional role to the work of CDWs who were working with specific ethnic groups did not appear to reap the same benefits as having a CDW dedicated to older people.

Engaging with established community groups as a means of accessing BME populations and delivering specific objectives for targeted communities has also been fruitful in Leeds. Accessing the community in this way has allowed workers to develop their skills and gained some trust and credibility. Stand alone initiatives were not as successful.

In **Devon, Sahara**, a BME mentoring project, has found employing strategies to directly access people successful.

- Workers have knocked on doors of potential service users
- Workers have got referrals by maintaining relationships with community organisations, landlords, postal workers', families and carers

Sahara has also developed courses which work to overcome initial barriers of engaging with BME elders. For example an Arabic class, a culturally acceptable activity, which lessened family anxiety at having an elder relative engage with an external, perhaps unknown, organisation. Having groups which appeal to the needs and interests of members has ensured continued attendance.

Additionally all mentors at Sahara were trained in communication and life skills such as maintaining persistence and how to overcome initial rejection from BME elders to become involved in groups.

In Birmingham **Future Health and Social Care** use religious cultural events to access communities they find difficult to penetrate.

Sharing voices, a voluntary sector organisation in **Bradford**, are often contacted by Mental Health services to help with people who they have failed to engage with. They are often able to reach these people through:

- Employing practical tools like home visits
- Showing consideration and understanding of family customs, the role of elders
- Understanding other culture considerations, religion, spirituality and language
- Being able to sign post people to community and statutory services which are appropriate to an individuals needs
- Having capacity in many community languages including Urdu, Punjabi, Hindi, Gujarati, Bangladeshi and Polish.

In **Leeds** and in **Bradford** dementia cafes have found that by naming the cafes in ways that do not associate them too closely to dementia or mental health they can reduce some barriers.

2.2 Tailoring services to the needs of target group

Several organisations have gone to great lengths to cater to the needs of those they wish to attract. For many this has paid dividends; all of the case studies evidenced below are often operating at maximum capacity. Several people were willing to share with us the elements they put in place to respond to the needs of the community.

Mind, a national mental health charity runs a group called **EKTA** offering cultural activities and a chance for South Asian service users in the Harrow area to come together and share experiences. Since it started in 2008 EKTA has continuously evolved to meet the needs of its members. The coordinator contacts a sample of members for feed back after every event and changes have often been made as a result of responding to this feedback. Below are some examples of the good practice shared by EKTA:

- Through using community languages, dietary observation, observing and respecting religious and cultural beliefs they are able to meet service users' religious, cultural and social needs.
- Food: the quality and type of food on offer has been key
- Venue: The venue should be known to the community, central with good disabled access
- Dates: trying not to compete or clash with other events locally
- Appropriate events: as the group does not attract younger people, activities are often tailored to an older group and activities such as seated gentle yoga, plays, visits to gardens and religious celebrations are appreciated by the client group.
- Advertising: Fliers are sent out every month. Knowledge of the client group and their families allows EKTA to print these in English and to follow up with phone calls for those for who this is not appropriate.
- Creating a social environment: members report creating relationships which are cemented by meeting up outside of the EKTA group. EKTA might also facilitate or inform of activities of interest outside of the monthly meeting (e.g. religious festivals which they might not normally know about together with the provision of subsidies mean those who would not otherwise have the opportunity can go).

Sahara in **Devon** had put a lot of effort into understanding and overcoming barriers which might prevent BME Elders accessing services. Whereas in mainstream services someone might feel self-conscious of factors which differentiate them from others, like wearing traditional dress or if they had a specific cultural need. At Sahara they offer culturally and age appropriate activities which negate the need for these anxieties.

Sahara ensure environments are conducive to people feeling comfortable and welcomed. Each mentor is aware of and trained in the complexities of cultural issues.

In **Bradford** the 16 **dementia cafes** throughout the city all have some common characteristics in order to maintain consistency of standards but each café is tailored to attract a particular community. Tailoring has resulted from a combination of information from the workers who run the café and understand their community, asking the community what they want and in some cases trying different things and failing.

In the example of **Bradford Well Being Café** hot, ethnically appropriate food is served. This is considered a must in attracting people of African and Caribbean origins. This is also the case in the café run by **Meri Yaaddein** in order to attract those of South Asian ethnicities. Music and activities in the cafes are also tailored to its members.

In **Leeds** an initial consultation was carried out to uncover what each community wanted from their dementia café, these were some of the results:

- South Asian community members tended to need to be engaged and informed before they would consider attending the café
- The African Caribbean café provides transport to attract people
- Appropriate food needed to be served at cafes
- An accessible location: **Sundar Mann**, a café catering for those of South Asian ethnicities, is held in an area of the city with a high proportion of South Asian residents. The location is attractive and well known to many as it was previously a school which they might have had connections with
- Activities: activities during the café often celebrate religious and cultural events, music is appropriate to the audience
- Language: Cafes are held in community languages.

My time in **Birmingham** is very proud of its reputation for offering faith and culturally sensitive counselling services. Even though a potential counselling patient may not wish to receive counselling from an ethnically matched counsellor it is important that this services exists as it suggests their needs will be met within the service.

2.3 Older activities

Having activities which are specifically tailored to the needs of older people is necessary to attract and maintain the interest of BME elders. We have seen in previous sections how this has been done at the **EKTA** group in **Harrow** with activities such as seated yoga and **Sahara** in **Devon** with a range of activities including gentle exercise and there is also evidence of it through the dementia cafes of **Leeds** and **Bradford** where activities might include a seated exercise session. Below is a case study from Telford & Wrekin which show how thought has been applied to the needs of a specific older client group.

Within **Telford and Wrekin Social inclusion services** there are specific groups for older people. 'Older' in this context may be used to describe anyone aged 45+ as those with learning difficulties tend to age earlier. The older peoples groups were established as services identified a need for older people to have a choice of activities that reflect their interests and needs. Thus, services developed a range of quieter activities that may be more suited to older people. These included reminiscing, pub lunches, visiting local sights, photography and general discussion groups.

3. Engaging with other Professionals

Almost every respondent contributing to case studies mentioned the need to link into other organisations or professionals to best meet the needs of BME elders. These links presented in a variety of ways.

3.1 Partnerships

Case study reports suggested successful partnership activity being key to good practice working with BME elders. This could be in the form of a partnership coming together to deliver work as in Leeds and Manchester or the membership of partnership boards and groups as in Derbyshire and Bradford.

SEVA, Manchester is a development partnership between 3 voluntary organisations that tendered for the Manchester Community Development Worker's Team funded through the *Delivering Race Equality in mental health care programme*.

In the first 6 months of operations SEVA conducted a scoping exercise to establish the foundations for continuing work with the BME communities of Manchester and consequently now employs 8 CDWs and a Team Leader. Each of these CDWs is hosted within one of the 3 partner organisations. 3 of the team have a remit around older people, each covering a range of ethnicities

The CDWs working with older people have linked into other organisations working in the field in several ways.

- Joining service user forums like Diabetes UK and Advisory steering groups like Manchester Social Care Mental Health Trust where they are able to highlight some of the key issues of older people from BME communities
- Trying to establish a charity to work with Sub Saharan African communities many of whom are destitute Asylum seekers unable to access mental health services.
- Linking in to other professionals running projects around mental health of elders
- Improving awareness of GPs and other frontline workers of services available in the community such as 1st language counsellors. It is intended 2010 will see production of a directory of community based services for frontline workers
- Working with the Dementias and Neurodegenerative Diseases Research Network (DeNDRoN), part of the National Institute for Health Research to raise awareness about mental illnesses such as dementia in the community.

Leeds Older People's and Disabled People's Strategic Partnership and Service

Development Team have found working in partnership with other service providers has been essential. There was no funding specifically dedicated to progressing the recommendations of an earlier report *The Challenge of Diversity* which looked at the prevalence of dementia within Leeds' BME communities. Thus, any service developments have relied on organisational collaboration.

As not all the **dementia cafes** in **Leeds** have secured funding continuation has also relied on contributions from partnership agencies.

Community development workers at **Derbyshire Gypsy Liaison Group** have been maximising the use of partnership links to improve access to mental health services by their community:

They are working on a two stage educational approach where firstly they engage with mainstream services to educate them about the Gypsy Traveller Showman (GTS) community and their needs. Secondly, they educate their own community to raise awareness about the mental health services that are available and able to meet their needs.

One CDW attends an older people's partnership group to improve statutory sector partners awareness of GTS Elders.

Crucial to the success of the BME CDW role at **Sharing Voices in Bradford** has been a good relationship with professionals working in the same or similar fields. Maintaining a good relationship has been facilitated by sitting on partnership groups where the CDW can raise any concerns with other statutory and voluntary sector professionals.

As a voluntary sector employee access to and influence in these groups is not easy to negotiate but has been vital in influencing appropriate services in the area. Feeding information from these groups back to the community has also been important in improving trust and understanding within the community.

There are examples of partners coming together to deliver dementia cafes in **Bradford**. The **Wellbeing Café** at St Pauls Church is staffed by people from Sharing voices, the PCT and Bradford Alliance Community Care (a voluntary sector organisation).

3.2 Relationship with GPs

Several case study respondents mentioned the need to engage with GPs in order to access potential service users, share information and knowledge of services and offer the best options to the service user.

Derbyshire Gypsy Liaison Group identified a gap in the knowledge and understanding of GPs surrounding the needs of their community. Whilst traditionally they would have sign posted people toward GPs they knew to be sympathetic to their community, more recently, through the CDW work, they are able to offer training to GPs and other frontline professionals in the area to improve their awareness of their community, thus improving the pool of sympathetic professionals.

My time in Birmingham has bi-lingual low intensity workers situated in 17 GPs surgeries signposting people to services in the community including their own.

At Elm Lodge Community MH Centre in Ealing there is a worker dedicated to improving links and relationships with GPs. A role valued for several reasons including:

- Good working relationships with GPs might reduce reluctance of GPs to thoroughly investigate physical causes of mental ill health before referral to mental health services and improve communication of results of any investigations
- Good communication with referring GPs could also improve GPs understanding of the working practices within facilities such as Elm Lodge, benefiting professionals and service users.

Future Health & Social Care found attempts to engage with GPs directly problematic. Thus FH&SC have made attempts to cement relationships with GP practice managers as a means of creating a referral pathway.

3.3 Relationship with other professionals

Many reported relationships with other professionals which helped facilitate work with BME communities. These professionals could be located within mental health related professions or in wider spheres.

In their attempts to assure referral pathways **Future Health and Social Care**, Birmingham has found links into other organisations important. They make the most of referrals from professionals other than GPs and site a member of staff in a hot desk in Birmingham carers centre as well as having representation at other local carer support groups within Heart of Birmingham.

The carer group run by Future Health and Social Care also invites professionals such as pharmacists in to speak to carers to improve their capacity to care for service users.

Bradford Dementia Cafes invite a range of professionals into their cafes to inform and help the community. Some of these are linked to mental health services like social workers. Others are drawn from further afield, such as fire and rescue officers coming to inform people about prevention methods and organisations that offer adaptations to the home to ease the impact of physical disability.

In **Manchester** CDWs from the **SEVA Development Partnership** facilitate their work with those from other cultures by relying on a sympathetic 3rd party, like a link worker from a similar ethnic background from another field.

In **Telford & Wrekin Social Inclusion Services** the BME Worker has found working with other council employees who work in a more general way with minority communities, like an Asian link worker, has helped overcome some barriers of trust in accessing some communities.

4. Staff

Central to the delivery of services to BME elders are staff, sometimes volunteers sometimes paid professionals. Either way good practice in mental health with BME elders was often dependent on good staff practices. Below are some general areas of good practices and case studies to illustrate.

4.1 Reflecting the community you serve

Matching staff to the community served was often considered valuable. This could be a match based on ethnicity or other factors. Matching staff language ability was also considered important by many; this is covered in more detail in the following section.

CDWs recruited by **SEVA Manchester** specifically reflect the community they serve. Profiles of the 3 CDWs dedicated to older people are shown below to illustrate this.

- One is from Sub Saharan Africa and has a specific community remit to work with Manchester Sub Saharan African communities and the Manchester refugee and asylum seeking communities. He is based at the African and Caribbean Mental Health Services.
- One is from China and has a specific community remit with Chinese, Vietnamese and Thai ethnicities. She is based at Wai Yin.
- One is of Pakistani descent and has a specific community remit with South Asian Communities. She is based at the Pakistani Resource Centre.

My time in Birmingham is staffed by a mix of paid staff and volunteers. The staff and volunteers we met were often ex-service users who had extensive experience within mental health services. Staff and volunteers also represented a wide range of ethnicities. These 2 characteristics were thought to be crucial to developing an understanding with service users and creating an accepting, non judgemental, non prejudicial environment for service users.

The **EKTA** group in **Harrow** runs on a combination of paid staff and volunteer help. Much of the vibrant and welcoming atmosphere witnessed at the EKTA group is attributed to the coordinator and staff.

- Volunteer help: volunteer contributions mean the program can meet its objectives without excessive costs; volunteers can also help reflect the ethnicity and community languages of service users.
- Staff do not differentiate themselves from service users, sitting at the same tables and chatting in accessible and often community languages.

4.2 Bi-lingual workers and language

Employment of community languages in services like dementia cafes and counselling has already been mentioned but the value of bi-lingual workers is so high it is worth mention as an area of good practice on its own.

Several case studies have highlighted how organisations have used community languages at events to help people feel at ease. However some reported the employment of specific bi-lingual workers as in these case studies.

Elm Lodge Community MH Centre is an NHS purpose built community support facility in **Ealing**. Offering bi-lingual workers is seen to be of key importance in working with the BME community at Elm Lodge:

- Workers who share similar cultural backgrounds to their clients have a better chance of understanding the cultural expressions, meanings and understandings of mental health. It is important to understand both older traditional customs and values as well as the more modern ways developing within some younger generations.
- Sharing and understanding cultures and customs can also help diagnostic procedures which may be based on western models thus making them more appropriate to individuals own life experiences. For example: overcoming gaps in information like dates of birth by thinking of ways of contextualising a service users age within historical events such as, for Indian service users, asking where they were and what they were doing at the time of Partition.
- Staff reported use of inappropriate slang by translators. Having bi-lingual workers who are also experienced in mental health fields can prevent misunderstandings between clinician and patient. This can benefit accurate diagnosis and appropriate respectful care.

Workers were also able to make suggestions which would further enhance the usefulness of this role:

- Ensuring the bi-lingual element of their work is written into job descriptions so if one person moves on they are replaced by someone with the same language capacity.

At **Future Health & Social Care, Birmingham** the benefit of bi-lingual carer support workers is threefold.

- When offering respite care, carer support workers are able to converse with service users in a variety of different community languages. This makes the service user more independent, empowering them and building up their confidence. It also helps with the delivery of personalised support that meets cultural needs
- When offering advice on benefits and help filling in forms carer support workers are able to translate forms.
- When advocating for carers, effective communication is integral.

My time in Birmingham offers 1-1 counselling in 18 languages. These language skills are seen as essential to the success of their talking therapies.

My Time often translates its courses delivering them in community languages that are appropriate to the audience.

A horticultural programme at **My Time** is run by an Eritrean man who speaks 5 languages and is training to be a Horticultural Therapist.

Mind in Harrow operates several programmes which rely on the language skills of its staff including:

- Somali Advocacy – provides advocacy to families who are referred to Mind in Harrow.
- Somali Research project – research into the impact on mental health of migration and issues in accessing services
- A CDW – currently working with Gujarati & Somali but is extending to others
- Community befriending scheme: where volunteers provide 1-1 emotional and practical support often in their own language.

4.3 Training staff

The training and/or knowledge and experience of staff was often seen as integral to good practice. Training was identified in several different forms all of which contributed to equipping a workforce to serving a diverse range of service users.

In **Bradford** all of the **dementia cafés** are staffed by a combination of paid workers from different organisations and volunteers who all work in a waiter/waitress style role during the cafe. Workers often have a role within their regular working lives within the mental health field and/or the African Caribbean community.

All volunteers have ½ day training covering depression, communication, and dementia.

As the CDWs at **SEVA development partnership, Manchester** come from a variety of working backgrounds and are hosted at different organisations with different access to training, their own training requirements have varied. However, these are things individuals have found useful.

- Cultural competency course aimed specifically at those working with asylum seekers and refugees from different ethnicities
- BME Breakthrough at the NHS leadership academy
- A diploma in counselling
- AN NVQ in film-making has helped one CDW support community projects who want to make dvds to improve awareness within their communities or communicate ideas to a wider audience
- Note was made of a 1 year post graduate CDW course which used to be run as part of the *Delivering Race Equality in mental health care action plan* at Salford University.

A note of caution around training was voiced by the CDWs however. They were keen that training which they undertook within their time-limited role should be transferable. Training should be both useful to their current role and also to them as professionals in the long term. At the same time, anxiety was voiced about some training that appeared to be offered or attended just so that a box could be ticked despite the fact that it was expensive and unlikely to achieve any professional development, skill advancement or qualification.

Staff at **Future Health & Social Care, Birmingham** continuously have their training updated to meet the needs of their client group. This can be in-house or externally sourced training which is often hosted by Birmingham and Solihull Mental Trust and can include:

- Training on rights of carers, including benefit entitlement
- Carer awareness training
- Health and Safety
- Risk assessment
- Cultural competency training, especially if support is required for a client group they have not previously encountered

In **Telford & Wrekin**, Social Inclusion Services identified the need for all staff to be capacity built in cultural competence. The rationale for this is so that all staff feel confident they can meet the needs of service users and so parents and carers have an access point other than the BME worker.

In **Leeds Dementia Cafes** are supported by a mix of volunteers and paid workers within the social care or health field. All the volunteers have some dementia awareness and are often ethnically matched to those who attend.

4.4 Community Development Workers

The CDW has recently evolved as part of the *Delivering Race Equality in mental health care* programme and is being put to good use throughout the country in many different ways. Here are some examples from our case studies.

At **Derbyshire Gypsy Liaison Group** 2 CDWs making up one full time post are making headway into improving access to mental health services within the Gypsy Traveller Showman community. We have seen previously some of the ways they are doing this through relationships with others working in this field. But working with the community and within a community based organisation they are able to overcome many cultural objections and also be creative when responding to specific needs of their own community.

One CDW is looking at ways to awaken an interest in traditional methods of helping with mental health problems and is working on an herbal chart as this form of intervention may be more appropriate for the community. Use of prescription drugs can be problematic for the community as there are fears around dependency. Also, the transient nature of the community can create problems around access to continuity of care.

CDWs at **SEVA development partnership in Manchester** work in a strategic role facilitating the building of bridges between local mental health service providers and the BME communities in Manchester. In this capacity they are able to see the impact of strategic decisions on the communities they are linked into.

- Working through community organisations they are able to inform the community of decisions made within statutory organisations and also consult with groups to try and influence policy.
- CDWs often have language skills to work with the communities they are serving. If the CDW does not have the language skills an interpreter will be used when consulting or informing the community.
- Working with people who shared their own ethnicities appeared to reap most rewards.
- One CDW delivered a narrative based psycho-social intervention translated in South Asian languages which was aimed at improving awareness around mental health to different groups within the community.

The Community Development Worker (CDW) at **Sharing Voices, Bradford**, tasked with working with BME Elders, gave us an insight on what was required to achieve success in his role and thus in the community he served.

Addressing low levels of information and knowledge within BME communities:

Sharing Voice CDWs have found that many BME elders diagnosed with mental ill health may have been given little information (or to have been unable to absorb the information that they were given) about their diagnosis and prognosis.

The CDWs had often had to address the fall out from health professionals making assumptions made based on an individuals age and ethnicity.

Often clarification of conditions, medication etc is the starting point of work with BME elders. This might include dispelling myths about mental health problems or acting as a translator/advocate with mental health professionals.

Engaging hard to reach individuals: (details in previous sections)

Ability to work outside the confines of the statutory sector:

Some of Sharing Voices success may be attributable to the increased freedom enjoyed by a voluntary sector employee which may not be afforded to a statutory service employee. Thus they may be able to not only identify appropriate services and signpost people into them but also to 'hand hold' them through the initial contact with the service.

Being separate from mental health services and being perceived as such is important.

4.5 Other dedicated workers

The dedicated BME worker at **Telford & Wrekin Social Inclusion Services** provides a similar role to the CDW but within Learning Disability services. During her time in post she has initiated and secured several advantages for BME service users:

- An initial mapping exercise recorded correct information on services users. Details like religion, ethnicity, marital status, dietary needs and preferred spoken language were collected comprehensively where previously a poor level of information was held about services users. Having this information and ensuring it was shared between the 5 centres has helped meet the needs of individuals.
- Recognition of the need for the workforce to move toward being more ethnically and linguistically representative of local communities
- A gap in parent and carers knowledge and understanding of the services was identified as a result of a scoping exercise. This was addressed and also gave parents and carers a point of contact which had been missing previously.
- Also identified in the scoping exercise was the need for translated information for reports sent home on service users progress
- Measures to accommodate the needs of some ethnic groups were employed e.g. prayer mats, posters and books on different religions as a staff resource and halal food was provided at one of the centres.
- Hosting events or accessing external events which celebrate the different cultures service users represent. These events often served to educate a wider group in order to improve understanding.

5. The Importance of Location and Environment

Throughout case studies we heard how location and environment were central to attracting and continuing to attract BME elders to services. Locations often had to be central, familiar and disability friendly. Environments had to be welcoming and to consider the needs of the particular groups they are trying to attract.

My Time is based in a location in **Birmingham** central to many BME communities, in a building known to the community that is also used as an asylum seeker and refugee drop in service.

Even though the building is partly within a church and partly attached to the church this has not proved an issue as people do not have to enter the area designated to worship. The advantages afforded by geography and familiarity overcome any drawbacks.

My Time will also deliver courses in alternative community venues when appropriate. An example given was a course for elderly Yemeni men held at the Yemeni Centre using a translator.

It is important for service users coming into My Time that they are in a safe and secure environment where they do not have to explain their mental health problems.

At the Well being Café in Bradford workers have found creating the right environment has been instrumental in attracting BME elders and maintaining their patronage. It achieves this in several ways:

- The relationship built between staff and the people who attend the café contributes to the ambiance; staff are careful not to speak or dress in a way that might make people feel uncomfortable or create formality and whilst they might join into conversation they respect the need for people not to have company imposed upon them.
- Creating a social environment: The objective of all the cafes is the prevention of mild to moderate mental health problems by addressing isolation, offering respite to families and providing a social environment where people can regain friendships. People are known to socialise outside the café.
- Informal access to services: the cafes serve to help signpost people into services in a less formal way, this can be a GP, social or dementia services, or organisations which offer ancillary services like physical adaptations to homes.
- All the cafes within the city are co-ordinated centrally by a community involvement team and so have common characteristics which are intended to make the cafes welcoming. For example all cafes have a raffle, exercises and speakers.

Future Health & Social Care has a central office open to drop-in 9am- 5pm. They use a variety of venues and events to promote their service and run carer support groups. They have found the choice of location to be vital to make it accessible and to engage carers in the service.

6. Threats to Good Practice

Respondents spoke of factors which could threaten good practice in mental health care for BME elders. Some of these have been alluded to already: inappropriate use of funds for training in Manchester, not replacing staff with those with equal language skills in Ealing. Many other potential threats noted related to the nature of funding. In Leeds we reported that the depth of impact of a dedicated CDW for older people was compromised when funding for this specific role was withdrawn. Funding is often time limited in this area and getting secure funding to continue work is increasingly difficult.

Throughout the country we are starting to see doubt over continuity once DRE funding for CDW expires and that is starting to show in reports from some case studies.

In **Telford and Wrekin Social Inclusion services** the role of the CDW is not secure after March 2010. This prevents the CDW taking on new cases of service users wishing to access services as they may have to be abandoned mid way through helping them.

In **Manchester SEVA development Partnership** community development workers commented on how their work relied heavily on links into communities and with other professionals. These links can take time to secure and can often be based on personal relationships. Thus it is important there is consistency of staff as high staff turnover can result in the whole process of creating links having to be repeated. Without consistency of funding it is not possible to guarantee consistency in staff.

7. APPENDIX A

Below are descriptions of the organisations who kindly contributed to these case studies.

Sharing Voices, Bradford

Sharing voices is a voluntary sector organisation in Bradford that provides a service as a bridge between communities and mental health services for Black and minority ethnic (BME) communities.

Community Involvement Team and Dementia Cafes, Bradford

The Community Involvement Team in Bradford, among other things coordinates the 16 dementia cafes throughout the city. The Wellbeing café is one of several run throughout the city which started around 4 years ago and which more recently has been funded by Partnership with Older People (POPS) money.

This particular café is attended by 20-30 older people of Afro-Caribbean origin. However there are 16 other cafes around the city which cater for a variety of communities, others may also appeal to specific ethnic groups, like one run by Meri Yaaddein which caters more for South Asian elders and others still which cater for a geographic community.

SEVA development partnership, Manchester

SEVA (an Asian word meaning serving our communities) is a partnership between 3 voluntary organisations that tendered for Manchester Community Development Worker's Team funded as part of the Delivering Race Equality in mental health care programme. The 3 organisations are Wai Yin, the Pakistani Resource Centre and the African Caribbean Mental Health Service.

Leeds Older People's and Disabled People's Strategic Partnership

In 2002 Leeds Older People's and Disabled People's Strategic Partnership renewed a process of discovering and meeting the needs of BME elders with dementia in the city; this process continues today.

The founding stone of this process was their Challenge of Diversity report. This focussed on the prevalence of dementia within Leeds' BME communities, the understanding of dementia within different communities, the barriers to accessing existing services and the support needs of people from ethnic minority communities living with dementia. A conference and the employment of a development worker cemented early work in this area.

8 years on from this report Leeds is still working towards implementing its recommendations.

Sundar Mann Café, Leeds

Throughout Leeds there are 11 Dementia cafes which run every month. These include a South Asian Café named Sundar Mann (Beautiful Mind) and an African Caribbean cafe.

My Time, Birmingham

My Time, Birmingham was established 8 years ago as a faith sensitive counselling services. Since then it has expanded and now offers a range of services to mental health service users from a range of ethnicities. One stream currently operating is their 'expert patients programme'; a 6 week/2.5hrs per week program for people with ongoing medical problems like diabetes and anxiety. This is a free course, funded by the PCT to which people can self refer. Other work streams include self esteem and confidence courses, FACT – Family Action For Choice: working with families sometimes where there has been domestic violence; help with jobs and housing; a service user forum; and a horticulture program.

Future Health and Social Care

Future Health & Social Care (FH&SC) is a social enterprise established in 1997 which supports carers within the Heart of Birmingham.

Derbyshire Gypsy Liaison Group

Derbyshire Gypsy Liaison Group (DGLG) is a small self help constituted voluntary group, established 22 years ago, serving the whole of the of Gypsy, Traveller and Showmen(GTS) community in the Derbyshire area and beyond.

The GTS community in England is distinct from other minority communities in many ways. These are some examples which set this group apart.

- The size of GTS populations in each area. Communities are often too small to facilitate organised initiatives specific to their ethnic group such as the social groups that we see for other populations.
- Recent research suggested mortality rates for those from GTS ethnicities means there are proportionally fewer elders compared to others. This has impacted on funding and consideration for GTS elders by services and commissioners
- People from GTS ethnic origins may be transient which can prohibit diagnosis and quality of care
- This is a community which is well known not to

- access main stream services including health services
- Risk factors for mental health may differ from other populations
- Low levels of literacy
- Mental health is considered a 'dirty word' and pride often prevents people admitting they need help

Thus the numbers of Gypsy elders requiring mental health services are very small but numbers of services catering for them is even smaller. Without the provision of specific services others who have a more general remit step into the gap.

Telford & Wrekin Social Inclusion Services

Telford and Wrekin Social Inclusion Services incorporates facilities for those with Learning Disabilities. These services are education, training, employment or leisure.

Mind in Harrow

Mind in Harrow is a mental health organization which supports people experiencing mental health problems in Harrow to live independent and full lives. It is an independent charity affiliated to National Mind and part of a network of 188 Local Mind Associations.

EKTA group, National Mind

The EKTA (meaning unity) group has been offering a monthly meeting since 2008, offering cultural activities and a chance for South Asian service users to come together and share experiences. Over 50% of the 80 strong members of the EKTA group are over 60. Funding for this group comes through a national program called Time to Change, aimed at reducing stigma and discrimination in mental health. The funding, secured over 4 years, originates from the National Lottery and Comic Relief.

Sahara, Devon

Sahara is a BME mentoring project that is delivered and monitored by Hikmat in Devon. Hikmat is a project for BME elders (defined by Hikmat as 45 plus) that began in December 2005. Other than the activities of the Sahara project, Hikmat has a drop in centre in Exeter and also offers training, counselling, foot care and a carer service; all of which offer opportunities for social interaction and culturally appropriate activities.

Sahara supports older people from South and East Asia, the Middle East and North Africa who are feeling excluded and/or isolated to engage with the social and educational opportunities available in Devon.

Sahara employs 12 mentors who each have responsibility for a different group. The objective of these groups include: social inclusion, reducing isolation, identifying those who need access to statutory services and encouraging engagement. Groups are varied and include:

- a scheme to help people apply for their bus pass and organise trips out using the bus pass;
- a group which teaches Arabic in order to aid prayer reading;
- a women only group;
- a group which acquaints older people with domestic technology like gaming machines, digital technology and the internet. This also acts as an inter generational group as young people are used to help explain some technologies, in return elders teach skills like deep sea fishing.
- Sports and leisure groups including: Bengali men's badminton, a walking group and multicultural exercise group;
- a prisoners support group; and
- North African cookery and beauty.

Ealing NHS Trust

Elm Lodge Community Mental Health Centre is an NHS purpose built community support facility in Ealing. There are 2 main sections of the building – a residential and a community unit. The latter offers services including a day care centre and access to health and social care advice and practitioners.

PART 5

Films on Dementia Active Ageing Volunteering, Policy

A FILM RESOURCE: 4 Films on One DVD

FILM 1: DEMENTIA MATTERS: ETHNIC CONCERNS (1999) A first European film in the area – 27 minutes

Dementia affects anyone irrespective of ethnicity. So why do people from Black and minority ethnic groups miss out on care? Can anything be done, now and in the future as the number of older people from minority ethnic groups increases? Discover the solutions by watching this first ever film to be made in Europe.

“PRIAE is to be commended for adding an impressive tool to its flagship CNEOPSA project...policymakers, managers, professionals, and BME communities will find important messages in this...” Rt. Hon. John Hutton MP, Minister for Health (speaking in 1999). A booklet on key facts, issues and proposals on dementia care accompanies the film and is available on request.

FILM 2: GET ACTIVE TODAY (2008) – 28 minutes

A motivational resource which Activates, Inspires and Motivates BME elders to be more active - working with them rather than on them. The film is produced by True North Productions narrated by Professor Jim McKenna of Leeds Metropolitan University, Carnegie Research Institute, Centre for Active Lifestyles. Elders from the South Asian, African, African Caribbean and Chinese communities demonstrate a range of culturally sensitive physical activities, which are appropriate for older people in their communities and they highlight the benefits of being active in dance, games, exercise, walking, and simply having an attitude of ‘living well’.

FILM 3: PROGRESSING POLICY WITH PASSION (2006) – 5 minutes

Narrated by Jon Snow, Channel 4 News Broadcaster, Progressing Policy with Passion is an introduction to the work of PRIAE, the Policy Research Institute on Ageing & Ethnicity, and to the issues that matter to Black and Minority Ethnic (BME) Elders in the UK. It makes the case that “in old age, being a minority should not be a disadvantage”.

FILM 4: PLAYING OUR PART AFTER 50 (2000) – 28 minutes

PRIAE’s BAFTA launched film asks if Black and minority ethnic elders simply put their feet up as they approach old age? Is it true that they are only concerned with care issues? Meet 5 elders in this film who will convince you otherwise. And they are not exceptions. The purpose of Playing Our Part After 50 is to show the contribution of Black and minority ethnic elders in different walks of life and to use it as an example to encourage others to show that helping, contributing and volunteering matters.

“Do not ask what society can do for you, but what you can do for society is the message that the ‘ethnic elders’ interviewed in this film unfailingly convey... it is a gift which we dare not accept lightly”
– A. Sivanandan, Institute of Race Relations. A guide accompanies the film and is available on request.

APPENDIX 1

An Extract on Recommendations from PRIAE's Film Guide Dementia Matters Ethnic Concerns

Key Recommendations

PRIAE has made a number of recommendations to organisations, professionals and carers in order to achieve change. These remain as valid as when they were first published, and have taken on a new pertinence in light of the NSF.

The essential strategies required are:

- Targeted developments and research must be put in place to assist ethnic minorities in accessing dementia care, as this has been so impoverished in the past. The involvement of mainstream statutory and voluntary providers is crucial due to the resource limitations of the dementia sector as a whole.
- An information and communication strategy needs to be put in place to increase awareness of dementia and support for carers. A number of cultural barriers continue to prevent ethnic minority groups from recognising the onset of Alzheimer's or seeking outside help.
- A training package needs to be put in place for health and social care professionals, allowing them to engage with the issues and develop their own appropriate strategies. PRIAE has begun running such sessions, and the support we have received indicates a willingness of health care professionals to participate.
- Mainstream organisations need to employ specialist minority ethnic workers, who are well placed to ascertain needs and anticipate problems. This would also help to stimulate appropriate care developments for the future.
- Policymakers need to recognise that minority ethnic organisations are essentially acting as primary providers of care in the absence of mainstream services. This should be reflected in future funding arrangements, as they currently suffer from scarce and short term resources.

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