

**COMMUNITY ENGAGEMENT PROJECT:
NIMHE Mental Health Programme**

**REPORT
OF THE COMMUNITY LED RESEARCH PROJECT
FOCUSSING
ON
GUJARATI-SPEAKING ASIAN ELDERS'
EXPERIENCES/VIEWS AND ATTITUDES OF
MENTAL HEALTH & MENTAL HEALTH SERVICES
IN HARROW**

May 2008

By



Mind in Harrow

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Damyanti Parmar
Janet Smith**

Funded by the Care Services Improvement Partnership and managed and supported by the Centre for Ethnicity and Health, University of Central Lancashire

May 2008



**For better
mental health**



Care Services Improvement Partnership **CSIP**

Report of the Community Led Research Project on Gujarati-Speaking Asian Elders' Views and Attitudes to Mental Health

Community Engagement Project

The CSIP Mental Health Programme

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PROJECT RESEARCHERS & AUTHORS

The following people were the key workers involved in the development and delivery of the project. Below is a brief biography of each individual

Arvind Joshi (Researcher & Co-Author) - Arvind is married and a carer of a daughter with a learning disability. He has been running an Asian friendship club for children and young adults with learning and mental disabilities for the last eight years. He is a member of Harrow Learning Disability Partnership Board. Apart from being employed as one of the researchers for this project, Arvind is also employed as a Stepping Stones Carer's Worker at Mind in Harrow. As Arvind has experience in learning disability, he decided to become involved in this project to know more about mental health issues.

Damyanti Parmar (Researcher & Co-Author) – Works part-time for Harrow Music Service, Community & Cultural Services, Harrow Council. She decided to do this research project as a challenge and as part of on-going personal learning and development studies with the Department of Voluntary Sector Studies at the University of Wales, Lampeter. She is very interested in community building and development work.

Janet Smith (Co-Author) – Has managed Mind in Harrow for 13 years. She is committed to improving services for Black and minority ethnic groups in Harrow and believes in the importance of incorporating non-Eurocentric perspectives into mental health care.

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Gayatri Satsang Mandal
Harrow Healthy Living Centre
Husseini Mosque
Sangat Advice Centre
Shakti Mandir
Shravik Satsang Mandal
Sneh Care Day Centre
UK Asian Women's Conference (North London)

The Steering Group

The steering group membership included local people with expertise and knowledge of the community, professionals with links to decision makers and planners in the borough and the UCLan Support worker:

- Carol Harrison-Read, Sector Manager, Central and North West London Foundation Trust, Harrow Mental Health Services and chair of the local Diversity Subgroup of the Mental Health Partnership Board
- Joanna Hicks, Community Engagement Research support worker, University of Central Lancashire
- Dr Claire Hilton. Consultant Psychiatrist, Central and North West London Foundation Trust Older People's Services
- Arvind Joshi, male researcher for this project, Mind in Harrow.
- Jayshree Joshi, Carers' Project worker, Sangat Advice Centre, and local resident
- Damyanti Parmar, female researcher for this project, Mind in Harrow
- Chandrakant Shah, local resident, and Mind in Harrow staff member
- Janet Smith, Chief Executive, Mind in Harrow
- David Truswell, Focus Implementation Site Lead, Central and North West London Foundation Trust

CONTENTS	page no.
EXECUTIVE SUMMARY	6
1. INTRODUCTION	8
- The Centre for Ethnicity and Health Model of	
- Community engagement	
- The focus of this report	
- Delivering Race equality to Asian elders in Harrow	
- Aims & Objectives of the study	
2. METHOD	15
- Recruitment and support of workers	
- Ethical issues	
- Selection of Sample	
- Access issues	
- Data analysis	
3. RESULTS	17
- Core Data – List of Tables	
1. Age Range	
2. Gender	
3. Ethnicity	
4. Country of Birth	
5. Nationality	
6. Length of Time in the U.K.	
7. Religion	
8. Sexual Orientation	
9. Disability	
- Interviews with Mental Health Service Users	
- Interviews with Gujarati-speaking Elders	
- Interviews with Carers	
4. DISCUSSION	58
- LIST OF KEY THEMES	
- Factors Contributing to Mental Health	
- Causes of Memory Loss	
- Pressures on Carers	
- Stigma Surrounding Mental Illness	
- What People Find Helpful	
- Equality of Access, Cultural Sensitivity of Services, Communication and Information	
- Choice of Culturally Appropriate Services/Therapies	
- Summary	

5. RECOMMENDATIONS	71
- Mental Health Services to become more culturally sensitive	
- Pro-active recruitment of Gujarati-speaking workers	
- Promote training and capacity building work	
- Local Gujarati speaking communities/groups to be empowered by training and supporting 'Community Champions'	
- PCT, Harrow Council and other mental health service providers to expand and support role of voluntary sector organizations.	
6. AUTHORS' REFLECTIONS	75
- Good partnership	
- Challenging assumptions	
- Satisfying and rewarding work	
7. APPENDICES	77
- Tools for data collection – Interview Questions for Users, Carers and Members of the Public	
- Information Sheet & Consent form	
- Leaflets	

EXECUTIVE SUMMARY

This report explores Gujarati-speaking Asian elders' understanding and perceptions of mental health and the services available in the Borough of Harrow.

The project followed the University of Central Lancashire (UCLan) Model of Community Engagement. This meant that the research was conducted by members of the Gujarati speaking community, who were trained and supported in their work by UCLan. The project was one of 80 similar projects conducted across England during 2005-2008, exploring issues relating to the government's Delivering Race Equality in Mental Health Care Strategy.

30% of Harrow's residents are South Asians, with the largest group being Gujarati speakers. Logistical and financial constraints meant that we needed to restrict the research sample. Whilst recognizing that this would exclude South Asian speakers of other languages from the research, this in no way diminishes our recognition of the needs of other groups in Harrow. The research thus focused on Gujarati-speaking Harrow residents.

50 people were interviewed using an in depth qualitative method with some semi-structured questionnaires for quantitative information – 17 users of mental health services, 12 of their carers, and 21 members of the public not known to be using services.

We analysed data for the following issues for the three groups:

- Their understanding and perceptions of mental health and its origins, including views about memory loss
- Factors influencing their take-up of services
- Their views of treatments on offer
- Their coping skills under present circumstances and what they find helpful

In looking at factors which had impacted on respondents' mental health, the experience of migration, losses, life events and physical ill health were major contributors. In addition many believed that there was a religious explanation and that it was their karma¹ to suffer in this way. Memory loss was seen to be as much due to mental stress as age-related. All respondents were keen to use

¹ Karma - A belief in cause and effect – similar to “you reap what you sow”, either in this lifetime or a future lifetime

services, but were often held back by accessibility issues, whether of transport, language or poor culturally-specific provision.

It was clear that there were many pressures on both the users and the carers of those who experienced mental ill-health – isolation, their own ill-health, inappropriate and ethnically insensitive aspects of services, ignorance of mental illness and of services. Carers generally accepted their role due to their cultural and religious background. Stigma and prejudice were perceived to be strong in the community. People drew a complex picture of family relationships, which were for some a source of great support and for others great stress, and even exacerbation of mental ill health.

It emerged that people were extremely resourceful and utilized a wide range of activities and support systems, one of the main ones being the family, despite the caveats above. However they highlighted major areas of ignorance in relation to both mental health awareness in all three groups and in relation to services and facilities available. Translation and interpreting services remain core issues to be addressed, along with the need for awareness-raising among the South Asian community and training professionals in cultural competence. Moreover the basic requirements of appropriate food and activities remain largely unaddressed also.

The implications of these findings are addressed in a number of recommendations:

- All Harrow mental health services should recognize and offer Gujarati-specific service options and improve cultural sensitivity of services
- The services should pro-actively recruit Gujarati-speaking workers
- To promote capacity building in the local communities, work should be undertaken there to improve the information available, create positive links between the cultural needs of the Gujarati-speaking Asian elders and service providers.
- Provide training opportunities to raise awareness and increase knowledge in both the Asian community and among professionals and also for service users and carers who have identified that they would value much more information, knowledge and awareness of mental health issues.
- Establish Community Champions within the community to capacity-build and increase public knowledge long term. Evidence is that there is the good will to progress this initiative. Gujarati speaking elderly communities and service users should be involved in monitoring and reviewing the services, and in the development of new ways of reaching those in need.

INTRODUCTION – THE CENTRE FOR ETHNICITY AND HEALTH’S MODEL OF COMMUNITY ENGAGEMENT

Background to the community engagement model

We often hear the following words or phrases: Community consultation; Community representation; Community involvement/participation; Community empowerment; Community development; Community engagement

Sometimes these terms are used inter-changeably; sometimes one term is used by different people to mean different things. The Centre for Ethnicity and Health has a very specific notion of community engagement. The Centre’s model of community engagement evolved over several years as a result of its involvement in a number of projects. Perhaps the most important milestone however came in November 2000, when the Department of Health (DH) awarded a contract to what was then the Ethnicity and Health Unit at the University of Central Lancashire (UCLan) to administer and support a new grants initiative. The initiative aimed to get local Black and minority ethnic (BME) community groups across England to conduct their own needs assessments, in relation to drugs education, prevention, and treatment services.

The DH had two key things in mind when it commissioned the work; first, the DH wanted a number of reports to be produced that would highlight the drug-related needs of a range of Black and minority ethnic communities. Second, and to an extent even more important, was the process by which this was to be done.

If all the DH had wanted was a needs assessment and a ‘glossy report’, they could have commissioned researchers and produced yet another set of reports that may have had little long term impact. However this scheme was to be different. The DH was clear that it did not want researchers to go into the community, to do the work, and then to go away. It wanted local Black and minority ethnic communities to undertake the work themselves. These groups may not have known anything about drugs, or anything about undertaking a needs assessment at the start of the project; however they would have proven access to the communities they were working with, the potential to be supported and trained, and the infrastructure to conduct such a piece of work. They would be able to use the nine-month process to learn about drug related issues, and how to undertake a needs assessment. They would be able to benefit and learn from the training and support that the Ethnicity and Health Unit would provide, and they would learn from actually managing and undertaking the work. In this way, at the end of the process, there would be a number of individuals left behind

in the community who would have gained from undertaking this work. They would have learned about drugs, and learned about the needs of their communities, and they would be able to continue to articulate those needs to their local service providers, and their local Drug Action Teams (DATs). It was out of this project that the Centre for Ethnicity and Health's model of community engagement was born.

The model has since been developed and refined, and has been applied to a number of areas of work. These include: substance misuse, the criminal justice system, policing, sexual health, mental health, regeneration, higher education and asylum seekers and refugees.

New communities have also been brought into the programme: although Black and minority ethnic communities remain a focus to the work, the Centre has also worked with young people, people with disabilities, service user groups, victims of domestic violence, gay, lesbian and bi-sexual and trans-gender people, women, white deprived communities, rural communities.

In addition to the Department of Health, key partners have included the Home Office, the National Treatment Agency for Substance Misuse, the Healthcare Commission, the National Institute for Mental Health in England, the Greater London Authority, New Scotland Yard and Aim Higher.

The key ingredients of the model

According to the Centre for Ethnicity and Health model, a community engagement project must have the community at its very heart. In order to achieve this, it is essential to work through a host community organisation. This may be an existing community group, but it might also be necessary to set up a group for this specific purpose of conducting the community engagement research.

The key thing is that this host community organisation should have good links to the defined target community, such that it is able to recruit a number of people from the target community to take part in the project and to do the work. The target community may be defined in a number of ways, often by ethnicity, but also age, gender, sexual orientation, geography or a type of difficulty such as domestic violence.

It is important that the host community organisation is able to co-ordinate the work and provide an infra-structure (e.g. somewhere to meet; access to phones and computers; financial systems) for the day-to-day activities of the project. One of the first tasks that this host community organisation undertakes is to recruit a number of people from the target community to work on the project.

The second key ingredient is the research task that the community undertakes. According to the Centre for Ethnicity and Health model, this must be something

that is meaningful, time limited and manageable. Nearly all of the community engagement projects have involved communities in undertaking a piece of research or a consultation exercise within their own communities. In some cases there has been an initial resistance to doing 'yet another piece of research', but this misses the point. As in the initial programme run on behalf of the DH, the process and its outcomes have equal importance. The task or activity is something around which lots of other things will happen over the lifetime of the project. Individuals will learn and new partnerships will be formed. Besides, it is important not to lose sight of the fact that it will be the first time that these individuals have undertaken a research project.

The final ingredient, according to the Centre for Ethnicity and Health's model, is the provision of appropriate support and guidance. It is not expected that community groups offer their time and input for free. Typically a payment in the region of £15-20,000 will be made available to the host organisation. It is expected that the bulk of this money will be used to pay people from the target community as community researchers. A named member of staff from the community engagement team is allocated as a project support worker. This person will visit the project for at least half a day once a fortnight. It is their role to support and guide the host organisation and the researchers throughout the project. The University also provides a package of training, typically in the form of a series of accredited workshops. These give participants in the project a chance to gain a University qualification whilst they undertake the work. The support workers will also assist the group to form an appropriate steering group to support the project.

The steering group is an essential element of the project: it helps the community researchers to identify the community they are engaging with, and can also facilitate the long term sustainability of the projects recommendations and outcomes. The community researchers undertake a needs assessment or a consultation exercise. However the steering group will ensure that the work that the group undertakes sits with local priorities and strategies; also that there is a mechanism for picking up the findings and recommendations identified by the research. The steering group can also support individuals' career development as they progress through the project

The UCLan community engagement team

The community engagement team comprises of senior support workers, support workers, teaching and learning staff, administration team and a communications officer. They work across a range of community engagement areas of specialisation, within a tight regional framework.

Programme outcomes

Each group involved in the Community Engagement Programmes is required to submit a report detailing the needs, issues or concerns of the community. The qualitative themes that emerge from the reports are often very powerful. Such

information is key to commissioning and planning services for diverse and 'hard to reach' communities. Often new partnerships between statutory sector and hard to reach communities are formed as a direct result of community engagement projects.

For example, in 2005-06 the Substance Misuse Community Engagement Programme was externally evaluated. This concluded that:

- the Community Engagement Programme had made very significant contributions to increasing awareness of substance misuse and understanding of the substance misuse needs of the participating communities. It also raised awareness of the corresponding specialist services available and of the wider policy and strategy context.
- the Community Engagement Programme had enabled many new networks and professional relationships to be formed and that DATs appreciated the links they had made as a result of the programme (and the improvements in existing contacts) and stated their intentions to maintain those links.
- most commissioners reported that they had gained useful information, awareness and evidence about the nature and substance misuse service needs of the participating organisations.
- all DATs reported positive change in their relationship with the community organisations. They stated that the Community Engagement Programme reports would inform their plans for the development of appropriate services in the future.
- A significant number of the links established between DATs and community organisations as part of the Community Engagement Programme were made for the first time.
- The majority of community organisations reported their influence over commissioners had improved.
- Training and access to education was successful and widely appreciated. 379 people went through an accredited University education programme.
- A third of community organisations in the first tranche reported that new services had been developed as a result of the Community Engagement Programme.
- The vast majority of participants and stakeholders expressed high levels of satisfaction with the project.

The capacity building of the individuals and groups involved in the programme is often one of the key outcomes. Over 20% of those who are formally trained go on to find work in a related field.

DISCLAIMER

The views expressed in this report are those of the people who participated in the research and of Mind in Harrow which undertook the work. They are not necessarily the views of the Centre for Ethnicity and Health at the University of Central Lancashire.

THE FOCUS OF THIS REPORT

Since the year 2000 over 250 community groups have taken part in one or other of the Centre for Ethnicity and Health's Community Engagement Programmes. These were initiated by a number of important documents aiming to improve the quality of mental health services for people from BME communities. One of these was *Inside Outside*² which proposed a number of reforms in mental health to enable achievement of equality in treatment for people from a BME background, to reduce and eradicate ethnic inequalities in mental health service; to develop cultural competence and understanding; and to engage the communities in building better mental health services.

A second document, *Delivering Race Equality in Mental Health Care*³ provided an action plan to address discrimination in mental health services and to ensure the same quality of health and social care to everybody in the U.K. regardless of their ethnic background. This included the development of appropriate and responsive services to people from BME backgrounds. Most relevant for this research were the following expectations: a reduction of fear about mental illness; increased user satisfaction; a better choice of therapies; active involvement of BME communities in policy development, training professionals, and planning and providing services; and ensuring a capable workforce. This is addressed in more detail below.

Delivering Race Equality to Asian Elders in Harrow

Harrow is an outer London borough with the ninth most diverse population in England. 30% of the borough's 210,000 people are South Asian, either from the Indian subcontinent or from Africa. The latter originally came here as refugees or economic migrants. Most are Gujarati speaking (around 18%), either following the Hindu or Jain religion, but there are also some Gujarati-speaking Muslims.⁴ Gujarati is the main language spoken in the western part of India, in the state of Gujarat. All the participants who took part in this research had their origins there although most had settled in East Africa since.

There are an estimated 2,500 South Asians over 65, mainly concentrated in the South East of the borough, where the wards are among the highest locally on the government's Indices of Deprivation. There are higher rates of overcrowding and deprivation within the Asian communities than white communities in these wards. There are also significantly larger numbers of Asians aged 45-60, which leads us to assume that this group will increasingly need tailored services over the next decade and after. The older Asian community suffers higher than average limiting long term illness (60% Asian v 46% same age white population⁵), with

² Inside Outside. NIMHE 2003

³ Delivering Race Equality in Mental Health Care. DH 2005

⁴ Harrow Vitality Profile, 2004. Harrow Council

⁵ Harrow's Diverse Communities, 2001 Census. 2006 Harrow Council

women being less well than men, which in turn can bring secondary organic mental health issues such as dementia, and psychological issues of support for families. Moreover it is reported by local community groups that increasing, though unknown, numbers are bringing older dependent relatives from India and Africa in order to support them. This, and the general lack of empirical study in London of the Asian community, (in contrast to the African-Caribbean community) make it particularly relevant to explore this further.

Finally, it has been documented that while the prevalence of dementia and depression is similar in the BME population to the white population, they are poorly represented in old age mental health services,⁶ the Gujarati population apparently being no exception to this. Moreover with only 13 inpatient beds in Harrow for all older people with serious mental illness (the DH recommendation is 30 beds⁷) it is imperative that community care is the best possible for this group.

Mind in Harrow is a local mental health charity which has, over a number of years, developed knowledge and expertise in working with different BME groups in the borough, including strong links and a range of mental health projects with the local Gujarati-speaking South Asian community. It also has a strong ethos of user-empowerment and of hearing users' views, which has informed its own service development and led to improvements in statutory mental health services.

The document *Delivering Race Equality in Mental Health Care* has a number of objectives which are relevant for this research.

1. **Equality of access.** Experience of the Old Age Mental Health Service in Harrow is that Asian elders have lower referral rates to mental health services than their white counterparts – less than 10% of the referrals to secondary care are from the South Asian population. There is much anecdotal evidence that there is a high degree of stigma, fear and lack of awareness in the community about mental illness which leads to an unwillingness to access services. There is moreover little known about the community's attitude to dementia.
2. **Cultural sensitivity:** There are concerns that local services may not be culturally appropriate, or culturally sensitive. The idea of a family/community model of work may be more useful in an extended family household, which will challenge the Western dyadic patient/doctor model.⁸

⁶ Shah, A. Can the recognition of clinical features of mental illness at clinical presentation in ethnic elders be improved? *International Journal of Geriatric Psychiatry*. 2007; 22; 277-282

⁷ Raising the Standard: Specialist Services for Older People with mental Illness. 2006. Royal College of Psychiatrist

⁸ Fernando, S. *Cultural Diversity, Mental health and Psychiatry*. 2003. Hove. Brunner-Routledge

3. **Challenging stigma and fear:** it is unclear whether older Gujarati-speaking adults have negative perceptions of statutory services, perhaps finding that professionals lack cultural awareness or that treatments are inappropriate.

4. **Improvement in communication and information:** Older Asians are frequently at a disadvantage when attending services because of language and cultural barriers. While it is important to have qualified interpreters available, it is unclear whether some older adults would prefer to have a family member translate for them because of issues of confidentiality (not wanting an external member of the community to know about their mental ill health)

5. **Choice of culturally appropriate therapies:** it is unclear whether people would prefer the option of Ayurvedic/herbal/homeopathic medicines and treatments, rarely on offer in a Western medical setting.

6. **Training:** many health care professionals have limited knowledge of the Gujarati community and knowledge gained will be passed on to mental health professionals via training and seminars. Moreover as part of the Community Engagement model, the community researchers will receive training in mental health and research method, and the work will skill them up for further work in their community.

AIMS AND OBJECTIVES OF THE STUDY:

- To explore Gujarati-speaking South Asian elders' (users, their carers and members of the public over 60 years) understanding and perceptions of mental health
- To ascertain what factors influence their take-up of services
- To ascertain their views of treatments available and whether non-western methods would be preferable
- To increase the awareness of the local mental health professionals to the needs of the group
- To support capacity-building in the community via increased knowledge and skills gained by the community researchers.

METHOD

Due to resource limitations, it was decided to focus on the Gujarati-speaking population, this being the predominant South Asian group locally.

Recruitment and support of workers

The organisation recruited, through open advertising in the local press, two paid workers, one male and one female, from the local Gujarati-speaking community to be researched. Both were fluent in Gujarati and English. They were each employed one day per week for the duration of the project. They undertook the University of Central Lancashire training in mental health and in research methods, analysis and report writing, They received regular supervision and support from the Mind CEO, who also assisted in the write-up of the report, and from the University's Community Engagement Support Worker. They were also supported by the Steering Group.

Ethical issues

Ethical approval was obtained from UCLan (See Appendix). Using the NHS guidelines⁹, it was decided that this work was a mix of 'audit' and 'service evaluation', and as such did not require additional NHS Research Ethics Committee approval. Information and consent sheets were prepared and given to all respondents in both Gujarati and English. Confidentiality and Data Protection were explained fully in the sheet. All respondents were offered a fee for the interview. Potential risk issues to interviewers and to respondents were addressed and systems put in place in Mind in Harrow in the event of any difficulty.

Role of steering group

The role of the steering group was to support the delivery of the project; specifically:

- to oversee and guide the research process
- to work with local partners to ensure findings were taken forward into improving service delivery
- To facilitate opportunities for future professional development of the researchers

Selection of sample

The researchers wished to investigate the views of three groups:

- Gujarati-speaking older mental health service users
- Carers of Gujarati-speakers elders with mental health problems
- Elderly members of the Gujarati-speaking community not known to be using mental health services.

⁹ Defining Research. NHS National Patient Safety Agency. 2007

It was anticipated that the sample would include individuals from the three main faith groups – Hindu, Jain and Muslim. The Hindu and Jain groups were found through a purposive sampling method, with convenience sampling of members of the Muslim community. All participants were ethnically South Asian although some defined themselves by their nationality of origin. All spoke Gujarati fluently, with some also having fluency in English, Urdu, Somalian or Swahili.

Access issues

Through their own knowledge and in discussion with members of the steering group, the researchers gathered a list of local Gujarati-speaking faith, social and interest groups. They designed an information leaflet, in Gujarati and English, then set about arranging appointments to make presentations to these groups. Individuals were invited to contact the researchers by completing their details on the leaflet or telephoning, following the presentation. Of the faith groups, the Muslim community took the most time to access, partly because the month of Ramadhan delayed people's possible involvement.

Three types of semi-structured questionnaire were designed: one for mental health service users aged 60 or over, one for carers of people with mental health issues, and one for focus groups with members of the Gujarati-speaking public who were 60 or over. These were written in English, but translated by the bilingual researchers.

The majority of the work was undertaken by both researchers as interviewers, one asking the questions, and one making written notes on the questionnaire sheet. Most of the participants preferred to speak in Gujarati so the questions in English were translated into Gujarati as the interview went along, and notes were translated back and transcribed into English by the researchers during the interview.

Focus groups were held in public and community venues in Harrow and individual interviews of service users and carers mostly took place in the respondents' homes, occasionally in a day centre or office space.

All questionnaires were then anonymised, by removing names and assigning each individual a code. The questionnaires were analysed by recording answers to the UCLan core data and other quantitative questions on Excel spreadsheets for numerical analysis and tabulation. Descriptive and qualitative data was recorded on 31 sheets for thematic analysis. Case examples and quotes were included to highlight important issues and salient points.

The fieldwork was conducted between September 2007 and January 2008.

RESULTS – CORE DATA

Core data required by the University of Central Lancashire is shown in table form below. This covers Age, Gender, Ethnicity, Country of birth, Nationality, Language, Religion, Sexual orientation, Disability.
N=50

Table 1. Age Range

Age Range	Under 50	%	51-60	%	61-70	%	71-80	%	81-100	%	TOTAL
Users	0	0	2	12	11	65	3	18	1	6	17
Carers	3	25	2	17	6	50	1	8	0	0	12
Public	0	0	1	5	12	57	7	33	1	5	21
TOTAL	3	6	5	10	29	58	11	22	2	4	50

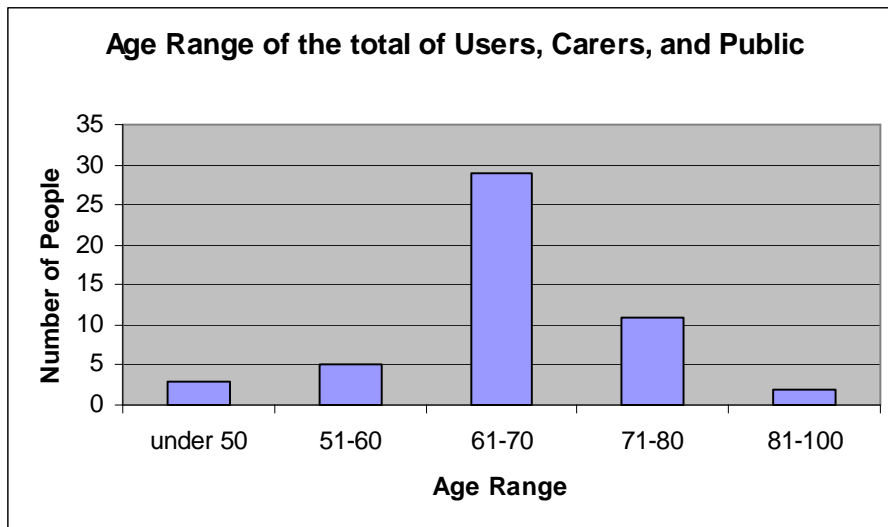


Table 2. Gender

Gender	Male	%	Female	%	TOTAL
Users	7	41	10	59	17
Carers	5	42	7	58	12
Public	10	48	11	52	21
TOTAL	22	44	28	56	50

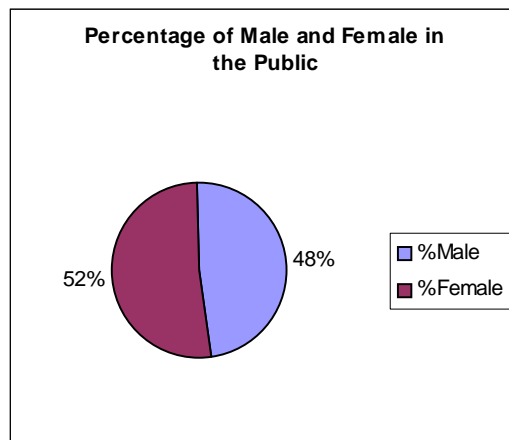
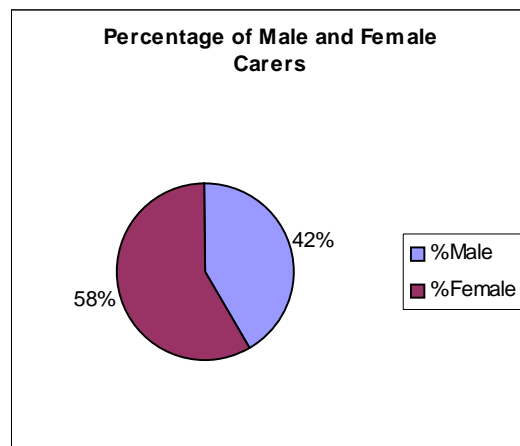
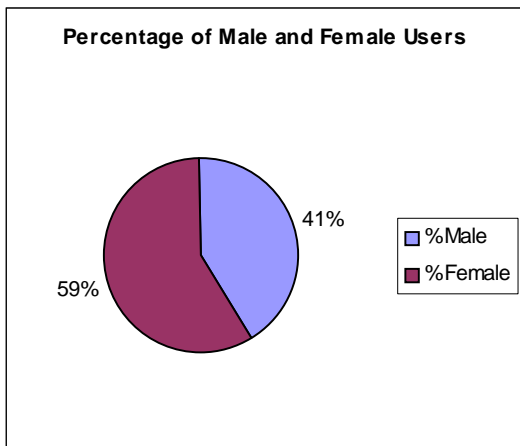


Table 3. Country of birth

Birthplace	India	Kenya	Uganda	U.K.	Somalia	Tanzania/ Dar'salam	United Arab Emirates	Total
Users	6	7	2	0	1	1		17
Carers	3	6	0	1	1	1		12
Public	10	6	3	0		1	1	21
TOTAL	19	19	5	1	2	3	1	50

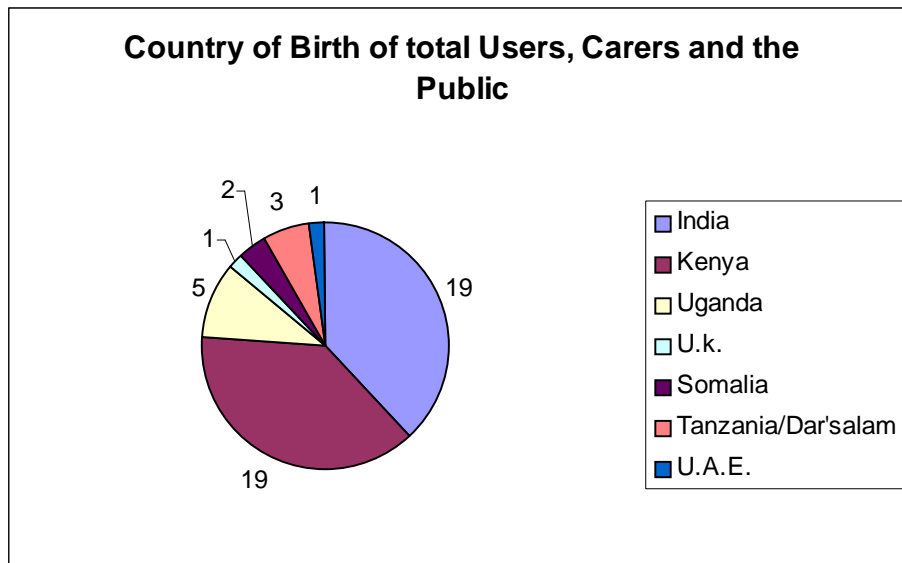


Table 4. Nationality

Nationality		British	Other	Total
Users		16		17
Carers		10	1	12
Public		20	Swedish (1)	21
TOTAL		46	2	50

Table 5. Length of time in the UK

How long in U.K.	Less than 1 year	%	1-5 years	%	6-10 years	%	11 years or more	%	TOTAL
Users	0	0	1	6	1	6	15	88	17
Carers	1	8	2	17	2	17	7	58	12
Public	0	0	0	0	3	14	18	86	21
TOTAL	1	2	3	6	6	12	40	80	50

How Long in U.K.

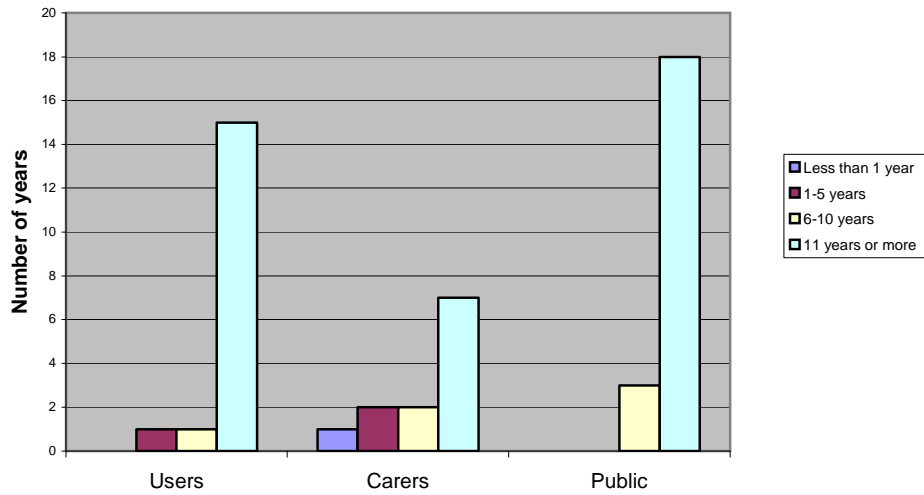


Table 6. Religion

Religion	None	Christian	Hindu	Muslim	Jain	Total
Users			13	1	3	17
Carers			7	1	4	12
Public			13	4	4	21
Total			33	6	11	50

Table 7. Sexual orientation

Sexuality	Hetero- sexual		Do not wish to answer		Total
Users	15		2		17
Carers	9		3		12
Public	15		6		21
Total	39		11		50

Table 8. Disability

Disability	No Disability		Disability		
Users	13		4		
Carers	11		1		
Public	17		4		
Total	41		9		

The physical disabilities from which people suffered ranged from difficulty walking, arthritis, cancer, paralysis, heart trouble and diabetes

RESULTS OF QUESTIONS ASKED

In line with the aims and objectives we explored older Gujarati-speaking South Asian adults' understanding and perceptions of mental health to ascertain what factors influence their take-up of services and their views of treatments available and whether non-western methods would be preferable

We have divided the groups into the following 3 sections.

- Mental health users over 60
- Gujarati-speaking elders over 60 not known to be using mental health services (members of the public)
- Carers

INTERVIEWS WITH MENTAL HEALTH SERVICE USERS

We interviewed 17 service users who were more than eager to talk and were not at all hesitant about sharing their views and experiences, despite all groups confirming that the community tended to avoid these issues.

Did you face any problems/difficulties [on arrival in the UK]?

Although this question was a general one, it was clear that the respondents felt that the difficulties due to their, often forced, migration had made a significant and long term impact on their mental health. The following were the most significant problems that were faced.

- Climate
- Strangeness
- Finance
- Isolation
- Language
- Racism
- Housing

Climate

Climate was a significant factor on arrival to UK and most of the participants had to adapt to the changes and different lifestyle they found themselves in.

"It was cold, not much fun; there was not enough heating."

"It was very cold. I thought of going back to Nairobi."

Strangeness

They did find life quite strange and difficult to start with and not what they expected or were used to.

“A new atmosphere. Having to do everything for yourself – a very hard life.”

“Everything in this country was different from the place we came from.”

Finance

Those who migrated from Uganda and had to leave everything behind, had to literally start from scratch to rebuild their life – which they stated had very stressful consequences with no money, job or even a house.

“Lots of problems. Not enough money. I had to borrow money from a friend for a ticket to the UK.”

“Loss of wealth since migrating from Uganda.”

Isolation

As most of those who arrived here had to begin earning a living again, they did not have the time to pursue leisure activities and develop friendships.

“It took time to make friends, develop a social circle.”

“I was very lonely, had no social life.”

Language

Language was also a barrier, most not having spoken English in their countries of origin. Here they had to set about learning whatever was necessary to manage their lives, another stress.

“I didn’t speak English well; I gradually learned enough to speak and understand.”

“There was a lack of translation service.”

Racism

Prejudice was spontaneously noted by just one respondent. However the research did not specifically explore this question.

“Racial problems - Our people were given hard work.”

Housing

It was also difficult to seek accommodation soon after arrival which a number of respondents found disturbing.

“Fear in a council house. Moving from house to house.”

“Housing was difficult –a rented property with not enough heating.”

Health Problems

The service users also reported here about the physical health and mental health difficulties they had experienced since arriving in the UK:

- Physical difficulties
- Personal mental health issues
- Suicidal thinking

Physical difficulties

Most users had physical problems that added to the mental distress they were facing.

“Losing my right eye- negligence on the part of the hospital.”

“Since losing my job, my health deteriorated. I started having medical problems. My health problems increased with my mental health issues.”

Personal mental health issues

It was distressing to find out about the various mental health problems the users were facing and also how they were coping.

“The trauma of health problems with my spouse, diagnosed with schizophrenia.”
“I’m suffering from depression.”

“The family called the police and I was taken to hospital against my wishes.”
“I feel helpless. I live in fear and anxiety; tearful most of the time. I had to leave my son in India; he was not able to join the family.”

Suicidal thinking

Some of the users had lost all meaning and purpose in life and felt they did not have any hope.

“I kept on telling the doctors I wanted to die – I asked the doctors to prescribe tablets to end my life.”

“I tried to strangle myself a few times.”

“Keeping issues to myself is making me suicidal.”

“There are days when I think of throwing myself at the traffic, but then I think of consequences and implications for myself and my family”

Who would you turn to for help if you were distressed?

Almost 50% of the participants reported that they now felt alone and said that they did not know where to turn to for help. (This was despite the fact that many later reported that they attended day centres and received services.) A few went to the library for solace, and others turned to prayer or getting help from MIND. All 17 participants attended their GP surgeries, with some also attending hospital. At least 6 participants depended on their family to escort them to the GP or the hospital.

What has helped you to cope?

Are there any activities you do which help mental well-being?

Participants were asked to choose from the following list: gardening, housework, meditation, singing/dance, reading, writing, yoga, attending groups, going to the temple, to masjeed (place of worship), exercise, walks; family events such as parties, outings, travel, seeing family, shopping.

Almost all participants felt that most of the listed activities benefited them in some ways and 12 participants also went swimming, to the gym, did art and craft activities, attended women's groups or watched TV.

8 participants felt better after prayers/mantras and two regularly performed meditation (vipasanna), and felt much better for doing so. However other participants could not do meditation as they found it difficult to concentrate.

One participant actually prayed regularly but only for death to come quickly and end his suffering.

Do you go to daycare or a daytime social club?

Does it help your state of mind?

Ten participants attended a Day Centre 1-2 days a week, with two others stating that it did not help them. Most said that they found it helpful, but were disappointed that no Asian food was provided, although they did enjoy the activities and having company of others. Two others either volunteered with Mind or went to Step Forward Only two did not go anywhere.

Any more options for elderly people? Suggestions?

Eight participants said they would like to attend an Asian day centre with appropriate facilities, and would like to be involved in activities, such as meditation/prayers. Six of these actually wanted a change in activities, such as arts and crafts, yoga, making jewellery, etc. at their present day centre.

A suggestion was also made for domestic home help to cope with daily activities. Another person said that they wanted to share their thoughts with someone. Four participants had no suggestions.

MENTAL HEALTH

What do you understand/your community thinks about mental illness/problems?

Almost all users felt that there is a lack of awareness and acceptance in the community.

Some felt that there is a need for training users and community members.

Six users did not feel accepted and a further six had experienced being labelled.

Most others felt that the community did not want to know about them, but gossiped.

Only one person felt that the community did support them

One user admitted not knowing anything about what the community thought of mental health issues as they did not go out at all.

Which of the following do you think might be mental health problems?

Memory loss, Emotional distress, Grieving, Sadness/Depression, Anxiety, Madness, Disturbed Behaviour, Hallucinations, Confusion, Suicidal.

Users agreed with all the above and had the following to add:

Anger, speaking to oneself, shouting/ or screaming, feeling there is no purpose or meaning in life, 'not necessarily hallucinations', bad dreams, helplessness, unhappiness with others and when alone, pacing up and down for help listening to voices/voices in one's head, frustration, self-harm.

General understanding of mental ill health

Users spoke with feeling and at length about their understanding and perceptions of mental ill health. These are collated under the following headings:

- Characteristics
- Causes
- Memory loss

Characteristics

Users gave the following examples of what they saw as characteristics of mental ill health:

Unhappiness, anxiety, being afraid to go out; restlessness ; constant suicidal feelings; self harm; hearing voices; lack of awareness of one's own dangerous behaviour.

"Hearing a spiritual voice."

"Pacing up and down."

"Anxiety, crying, distress, loneliness."

"Disturbed behaviour – shouting, talking to oneself."

Isolation

Users perceived serious feelings of isolation as being a major characteristic of their mental distress, and a contributing cause.

“Being alone in the house can generate the first signs of depression.”

“Crying alone, being disabled.”

“Not able to share my thoughts and feelings.”

“Staying at home all the time – my head is spinning.”

“Keeping things within myself- ending up taking an overdose.”

Causes

There were perceived to be many causes of mental illness and some users were quite aware of how they first started suffering. People’s past experiences and painful life events were seen as major causes, while some also felt it was unavoidable due to their karma.

Chance

“Mental health problems can come to anyone at any time.”

One’s past

“It started before my marriage, due to my ... upbringing.”

“Being fearful of someone attacking you in the present circumstances; being stuck in the past, living in fear, panic and insecurity.”

Life events

“Changes in lifestyle in this country gives you mental illness.”

“I have been caring for my husband for 45 years.” (A service user and a carer)

“My problems started after I got married and was not treated well.”

“My husband having a girlfriend – he’s now in India.”

“My son losing a big sum of money gambling. I am not able to forgive or forget what has happened.”

Bereavement

“Three brothers dying young and my husband having bypass surgery brought mental distress.”

“The shock of bereavement triggers problems; the shock of losing helpful family members.”

“Two miscarriages.”

“I feel like dying,[I have] nothing to live for since my son and husband passed away.”

Loss of work

Not being able to work.

“Having to leave my job as the office moved to Switzerland. I’ve not been working for the last 10 years.”

“I worked for 17 years in a factory. I had a car accident and was given redundancy on medical grounds. I also had memory loss.”

Karma

"You feel this is your karma – you have to suffer."

"I strongly believe karma causes it."

"Its punishment at times, of our own making, not karma."

Magic

"Sometimes I feel its black magic. Otherwise why is it happening?"

Memory loss

Almost all users thought that memory loss was a mental health problem and gave vivid descriptions of their own experience.

"I keep on thinking of the past, forgetting the present. I cannot remember what conversation I was having with my family or friends."

"I have had memory loss since my accident, and my redundancy from work was due to that."

"I do not feel like doing anything. [I have a] completely blank mind."

Causes of memory loss

However they did not believe that memory loss was caused by old age and gave their own reasons for the causes: illness, depression and anxiety, difficult life events.

"Memory loss is nothing to do with age. My mother of 92 has a terrific memory."

"One is forgetful because of stress, worry or health issues."

"I'm forgetful due to strokes."

"Shock, triggered by death or illness."

"Depression and anxiety causes one to forget things, as one is preoccupied with negative thoughts."

What do you think your community thinks about mental illness?

The following themes emerged from the users about what they felt the community thought.

- Awareness in the community
- Stigma and labelling
- Lack of help from the family
 - Neglect / avoidance
 - Responsibility
 - Conflict

Awareness in the Asian community

Most of the users did not feel the community was aware of mental illness or did not know how to deal with people who had problems.

"They ask a lot of questions when I attend community events. I feel uncomfortable."

"No understanding or awareness of the problems."

"The community is very selfish"

"They have no time to ask how we are. People in general have no understanding."

Some were also pessimistic about this.

"Our community will not change."

Stigma and labelling

They also felt that they were being labelled instead of being supported, even when they went for counselling.

"In India there is not a good response [to] mental illness. They call us 'Paagal (mad)."

"A counselling agency staff member called me 'Paagal' a long time ago."

"I do not trust any friends, only [people at] The Bridge."

"They gossip about the way we talk and behave, spread rumours."

"I find the community does not want to talk to me if they find out about [me]."

Lack of help from family

Some of the users were not being helped by their own immediate family and felt neglected, being avoided instead of being supported in their ill health. There was some evidence of conflict within the family and others felt trapped in family responsibility.

Neglect / avoidance

"My family does not often come to see me [in a sheltered home]."

"My husband has been living in Kenya as he does not like the weather in the UK. He likes to do his own thing."

"Relatives are far away and not able to share the pain."

Responsibility

"I got trapped in family responsibility."

"Brothers and sisters have not helped me, only my husband is supportive."

Conflict

"My mental illness increased after my mother-in-law came from India in 1975."

"Family members take advantage."

"My mother-in-law is not understanding."

"My husband dominates what goes on in the house." (weeping)

"I have no voice when other members are more dominant."

"I am very upset that my own family has betrayed me. In turn my son has developed depression as well."

What has been useful, what has helped you to cope?

Our research has made us aware that users used a wide range of strategies to cope with their illness.

- Help from family and friends
- Use of GP / medication
- Day centres and services
- Culturally specific support
- Religious beliefs
- Prayers and meditation
- Motivation
- Physical activities
- Classes
- Outings and travel
- Activities at home
- Transport

Help from family and friends

The family was essentially the crucial area of support for some, and friends were also useful for help with coping.

“I’m well taken care of by my family and children. I’m not aware of any other help.”

“I get very angry at times. The family is aware and tries to understand.”

“Sitting with my old friends. When I meet them I feel good.”

“Every Saturday we meet at clubs or pubs and have drinks from 12 to 2.”

“Sharing problems with other people.”

Use of GP / medication

We found that users were in general quite muddled about medication. Some had taken complexly inappropriate drugs on family advice, others had no idea about side effects and felt psychiatric medication made them worse. Ayurvedic medicine was mentioned as a possible alternative.

“I got medication for epilepsy from a family member. I should have gone to the GP. There was no guidance on the right drugs, and the side effects of the medication increased my mental health problems.”

“I went to the GP who prescribed drugs which I did not take.”

“Its difficult to access ayurvedic medicine.”

“Ayurvedic medicine helps. I took it for years.”

Day centres and services

There were mixed feelings about the support that users got from different centres, and mental health and other services.

“I recovered with support from workers at the Day centre I attend”

“The mental health services gives very good support.”

“The specialist team within the mental health services are visiting me.”

"I attend an Asian day centre once a week."

Community mental health team worker visiting

"Support from the council – help with rent. Free medical service."

"I do not like the Day Centre I go to. [There are] no activities as the people there are severely disabled."

"I attended a day centre once and did not like it."

Culturally specific support

Users were all fully aware of the need for culturally specific support and Facilities, and of the gaps in many day services.

"I prefer to go to an Asian centre."

"[There should be] day centres providing for cultural needs – food and relevant activities."

"Vegetarian meals: food must be improved to meet dietary requirements."

"Asian meals on outings".

Religious beliefs

These were important for most participants and they felt these did help them cope better. Some felt comforted, others relied on teachings and guidance.

"Religious beliefs have helped in knowing that suicide is not the answer."

"God protects, and is not the cause of suffering."

"Everything depends on God's mercy. All we can do is a 'dua'¹⁰ to take the pain away."

*"I go to the temple. They all look after me. I attend satsang¹¹
I get a lot of attention."*

However not everyone had been helped by religion:

I stopped going to the temple after my brother's son died young. I do not believe in God since then."

Prayers and meditation

These participants also got their strength from prayers and meditation: satsangs, meditation, yoga, mantrasⁱ prayers, and religious books.

"Hanuman Chalissa¹² – encouragement to pray."

¹⁰ (supplication/private prayer in Islam)

¹¹ (described in Indian philosophy (1) the company of the "highest truth," (2) the company of a guru (Spiritual guide) and (3) company with an assembly of persons who listen to, talk about, and assimilate the truth. This typically involves listening to or reading scriptures, reflecting on, discussing and assimilating their meaning, meditating on the source of these words, and bringing their meaning into one's daily life. People gathering together to exchange religious dialogue in the form of prayers, songs, etc.)

¹² (a religious or mystical syllable or poem, typically from the Sanskrit language).

*Vipaasanna*¹³, or retreat.

*“Listening to bhajans*¹⁴”

*“Bhajan and kirtan*¹⁵ sermons and devotional poems and ballads (at various homes, including my own.”

Motivation

Users’ personal motivation has been a very helpful force in helping them to cope with their mental health problems, sometimes supported by their religious beliefs.

“A ‘You can do it’ attitude.”

“Strong willpower is important, and having faith in God will help you get better.”

“Motivate yourself with determination.”

*“Believing in Dharma*¹⁶”

Physical activities

Although the users wished to get involved in physical activities, their health limitations and lack of encouragement by others prevented them from taking part. There were only a few who did participate in physical activities.

“I would like to get involved in activities, but I’m not fit physically.”

Classes

Some participants were finding these beneficial for their well-being and wanted more encouragement to learn.

“Attend college and learn new skills.”

“Develop creative interests and activities.”

“Maths tuition at the Day Centre I attend.”

“Computing at a mental health vocational centre.”

“I’d prefer to learn computing but I’m not able to concentrate.”

Outings and travel

Getting away, either on day trips, or going abroad, helped some users to feel better.

“Going abroad makes one feel better.”

Activities at home

Others preferred doing something in the comfort of their own homes such as sewing, cooking, doing puzzles. Listening to Asian radio was much appreciated.

¹³ (a form of Buddhist meditation)

¹⁴ A **bhajan** is a Hindu devotional song , often of ancient origin.

Great importance is attributed to the singing of **bhajans** with Bhakti , i.e. loving devotion

¹⁵ **Kirtan** (hymns with music),

¹⁶ Dharma – one’s purpose in life or that which signifies the underlying order in nature and life (human or other) considered to be in accord with that order

¹⁷ a free-standing musical keyboard instrument similar to a Reed Organ or Pipe Organ. It consists of free reeds and sound is produced by air being blown through reeds.

“Playing a musical instrument – the harmonium¹⁷

“Listening to a local Asian radio station/TV channels -

“Taking the dog for a walk - gives me company.”

Transport

The main issue for a number of participants was the availability or lack of transport for getting out to do activities or attend day centres and events.

“Getting transport because of my physical disability.”

“Transport is an issue, otherwise you get late for activities, which is very disappointing when attending a day centre.”

Any more options or suggestions?

Many of these suggestions are about the need for ethnically specific services. The lack of awareness in statutory centres about Asian food, and cultural activities, and the lack of ethnic-specific provision was noted by many users.

- Food
- Transport
- Activities
- Day and residential centres
- Help at home
- Outings
- Voluntary work
- Counselling, talking, befriending
- Interpreting
- Education

Food

“Cooking facilities for Gujarati people.”

“A proper lunch at centres, not just potatoes... otherwise I prefer to cook at home and eat proper meals before going out.”

“Cooking is done in one kitchen – I’m not able to eat chips as they are cooked with non-vegetable oil.”

Transport

“I have to depend on my daughter/others to make time for me for hospital appointments, GP, shopping.”

Activities

Yoga with others, Art and craft activities, puzzles, computers

Day and residential centres

“Activities in a day centre – yoga, exercise, a proper lunch; cooking and sharing together.”

“Watching the Asian TV channel in the residential home.”

"[There should be] more Asian homes in Harrow."

There were mixed views about whether it was better to have mixed groups – both with respect to ethnicity and severity of illness.

"...Mixed community groups – in Asian groups there is too much gossiping."

"[Residents] in day care centres should be put in separate groups – those with mild difficulties and those with severe. It makes you feel bad if [you see] others in a worse position. [You] feel more pain watching others suffer."

Help at home

Some users wanted more help in the home, although these needs linked more with age than mental ill health.

"Home help – cutting up vegetables... help with daily chores as I am not able to work and have difficulty preparing them."

"Free delivery of groceries"

Outings

Similarly, users wanted the opportunity for outings, day trips, and also help with shopping.

"Someone to take us out to outings and picnics."

Voluntary work

"Doing voluntary work – some admin."

Counselling; Talking, befriending

Counselling and befriending were valued services, but again users often preferred an ethnic-specific option.

"Resume the Asian Befriending Scheme."

"Counselling is useful if people are from a similar culture."

"Somebody to talk to even for an hour."

"Daily help to chat, besides household help."

Interpreting

Translation services were important but seen by some as insufficient, especially at clinics and hospitals."

Education

"Educate people to change their attitudes about mental health."

VIEWS FROM MEMBERS OF THE GUJARATI-SPEAKING ASIAN ELDERS OVER 60

**We interviewed 21 Gujarati-speaking Asian elders who were members of the public
In five focus groups, and the following questions were asked:**

MENTAL ILLNESS

What do you understand/your community thinks about mental illness/problems?

The number of respondents who felt that memory loss was a problem for older people was low, as most felt that this could happen to anyone at any time and other factors, such as stress and anxiety contributed.

Amongst the focus groups, most of the participants had some understanding and experience of mental illness, although four mentioned that they did not have much understanding.

Key themes:

- Avoidance
- Shame and stigma
- Ignorance of young people
- Knowledge and education

What do you think your family and community think about mental illness?

8 felt that there was a lack of awareness and understanding in the community

6 felt that the community does not accept mental illness

“The community is aware but does not want to accept it – tries to run away, avoid it.”

5 stated that families who had a member with mental illness did not tell or share with people outside the family.

4 thought that outside the family, the community did not recognize mental illness

1 said that the community had a very bad attitude, that people were ill-treated

“The family and community in some cases are not aware or are ignorant, or have very little understanding of what is going on”.

“Because you can’t see it, people are less sympathetic.”

1 said people did not admit to difficulties, because they would not be accepted and would be labelled

1 said that the younger generation did not understand

What is your understanding of memory loss?

3 people thought memory loss was due to ageing

1 thought it was not age-related at all

"Maybe its present from birth, your karma inheritance."

4 thought it was not (necessarily) related to ageing, but could be the result of difficult life events

1 thought it was due to one's karma

1 thought it was due to the menopause

2 said it was caused by one's lifestyle, not keeping the mind active

5 said it could happen to anyone at anytime, not necessarily old age.

"It can be triggered by events in your life – unfair treatment of widows, the restrictions of tradition, being criticized for your behaviour".

"It can happen at any time, even from a young age or birth, its nothing to do with age".

Which of the following do you think might be mental health problems?

Memory loss, Emotional distress, Grieving, Sadness/Depression, Anxiety, Madness, Disturbed Behaviour, Hallucinations, Confusion, Suicidal

Almost all respondents agreed with the above list with the following additions, which fell into the following broad groups:

- Classic symptoms of mental illness such as: hearing voices, feeling others were talking about them; being prone to self-harm, life not worth living
- Common descriptions of stress and anxiety such as not wanting to go out, sitting alone in a corner, blaming others for everything; being fearful; not liking anyone contacting them, feeling insecure, having an inferiority complex; anger, frustration, taking things personally, a negative attitude
- Unusual descriptions like - battles with the conscious and unconscious,
- Ordinary behaviour - running around, nightmares, one's mind lost in other things, being loud, seeking attention

What do you think causes it?

Seven choices were offered: Karma, magic, God, life events, old age, punishment and side effects of medication.

12 participants said they believed in Karma, life events, punishment and the side effects of medication.

4 participants believed in punishment for bad deeds, and all sorts of magic and witchcraft & side effects of medication.

5 participants believed in Karma, evil spirits & witchcraft, punishment & medication side effects.

Most respondents felt that karma, and punishment were major causes of mental illness, probably based on the belief systems held by this particular community. This was followed by life events and the side effects of medication. The side effects of medication prescribed for physical conditions were seen as a contributory factor to mental health problems, although some believed that side effects of psychiatric medication were sometimes wrongly attributed to mental illness.

"It can be triggered by events in your life - unfair treatment of widows, the restrictions of tradition, being criticized for your behaviour"

Other causes noted were: physical health, heredity, and one's own thoughts. Most of the people interviewed believed that physical causes were important.

Physical

"Overdose of medication; disturbing side-effects can contribute"

"Lack of activity or outings can cause mental illness."

"Being bed-bound"

"Physical illness can trigger it"

Heredity

"It can be present from birth, inherited, a genetic disorder."

"Mental health can be hereditary"

Besides the above it was interesting to note that other causes were identified: wandering souls; a bad lunar eclipse

Induced by thoughts

It was also noted that some members of the public believed that one's thoughts generated mental health issues/problems and also that it could happen to anyone at any time, at any age.

"It can be self-created by your own thoughts"

"Mental health sufferers have their own thoughts, they cannot mix with others"

"Its caused by a defunct mind."

MENTAL WELL-BEING

Which of these activities from the list in the question do you think would help people with mental health issues?

Hobbies, Gardening, Interpretation/Translation, Housework, Meditation/Prayers, Singing/Dance, Reading, Writing, Yoga/ExerciseGroups, Temple, Western Medication, Family events, eg. Parties, Ayurvedic/Indian medication, Talking to people, WatchingTV/Radio, Arts & Craft, Outings/Trips/Travel, Picnics, Counselling, Seeing Family, Shopping, Walks, Day Centre, Community events.

All of the participants felt that most of the above would help.

Do you and your community accept and encourage people with mental health issues and their carers into your community?

Several respondents felt that not much help was given. 5 participants felt community leaders were to be blamed for non-integration as they were non-accepting, did not support, and were critical of mental health sufferers.

Four participants said they were not aware of people with mental health problems, but they would like to accept and encourage them. One admitted knowing of a family hiding in shame and said they would like to help people with such problems. Three people admitted that neither they nor their community was involved in any way, and they would like to get more involved.

If so, how do you meet their needs?

5 participants said they accept and encourage them. They did this by inviting them into their prayer group.

In which of the following activities from the list in the question do you or your community encourage them to participate?

Satsangs, Community Events, Prayers/Religion, Rituals/Mantra, Exercise/Yoga, Talking to them, Family Support, Music/Dance, Outings, Arts & Craft, Transport, Learning Skills.

Members of the public spoke about their own activities and then related this to the involvement of people with mental health issues. Most of the participants felt that all of the above activities were important as it was absolutely necessary for mental well-being to keep the mind active. 5 said they encouraged users to be involved in all the listed activities. 13 said they involved users in prayer groups

One of the biggest issues was that community groups were structured around people with the same views being accepted and that meant that others did not feel welcome. People with mental health problems would therefore usually find it difficult to participate and some groups were not at all inclusive.

Suggestions to help involve mental health service users in the community

All participants wanted to get involved with service users, with support from voluntary organisations. Most wanted awareness to be raised in the community about integration. They also wanted training for young people. They had the following suggestions to help involve mental health service users in the community:

- Support to families
- Awareness-raising and training
- Transport
- Listening and support
- Groups
- Professional help
- Leisure activities

Support to families

Most of the members of the public that we spoke to were struggling on their own trying to meet their obligations to the family without any training. Some disclosed that they had caring responsibilities and mental health issues of their own and thought users would also need this support.

“The family needs support – voluntary groups relieving the family and helping the sufferer by talking, taking them out, building friendships....”

“Carers need training.”

Awareness-raising and training

7 participants would like help in receiving training, awareness and support from voluntary organizations on mental health issues.

They recognized that there was much to be done in the way of training to bring awareness to people, from carers to members of the community, who could then give better support to service users.

“There are still people out there...who may be suffering but have not come out, so we are not aware of their needs or how or where to approach them.”

“Awareness training for youngsters to help in temples.”

“Bring awareness to all through training/presentations.”

Transport

Some of the participants did express concern that Asian elders in particular would have great difficulty getting about for a number of reasons, including language barriers, physical problems and often being dependent on their spouse to take them around. Without a partner, they would have to depend on their children who were either too busy with their jobs or in different parts of the world.

“They need help with transport”.

“City appointments for special treatment can be difficult for older people.”

Listening and support

By listening and supporting people with such problems members of the public said that they hoped that they could lead a better life and become useful members of the community.

“Help them to become better and lead a better life with support and more understanding.”

“They need people who can give them time and listen and talk to them. Lots of love and acceptance [will] keep them happy.”

Groups

Members of the public suggested that groups of people with common interests, who worked together building various skills and creative activities, or empowering people would be more useful than just pitching those with similar problems together.

“Support groups to give confidence, self-esteem and respect.”

“Older people need encouragement to meet and exchange views – a special group [could] be set up.”

It was thought by some respondents that being exposed to people more unwell than oneself would not make users feel any better but rather more depressed.

“Groups with only mental health sufferers would not work better.”

Leisure activities

Members of the public suggested a range of leisure activities eg dancing and arts, but that community groups needed to become more user-friendly.

“Do garba¹⁸ with them – its part of acceptance.”

“Society, community groups, clubs and associations should be more user-friendly.”

Professional help

The group realized that there is a need to get specialized help from professional bodies to deal with complicated issues that emerge from the wide spectrum of mental illness.

“A person with skills is needed to help them relate.”

“Counselling is not easily accessible for people with cultural differences. There is a need for more appropriate services.”

Other themes which emerged

Some of these themes related to perceived triggers or causes of mental health problems:

- Effects of migration
- Isolation
- Families
- Loss and bereavement
- Gender issues
- Avoidance

¹⁸ Gujarati folk dance

Other themes related to ignorance, stigma and the need to raise awareness in the community:

- Shame and stigma
- Ignorance of young people
- Awareness and education

Triggers

Effects of migration

As with the users, a good number of members of the public acknowledged that migration had adverse effects on mental well-being.

“Not speaking English when everyone around is speaking the language – feeling left out.”

“Since coming to this country there are more mental health problems such as depression due to lifestyle, weather, eating habits etc. People do not greet each other, they’re just rushing around.”

Isolation

Members of the public recognized that this was a crucial factor in the early stages of mental illness/problems. Some people said, further, that if this was not addressed, it just made matters worse.

“Not being able to socialize and mix with others results in isolation, anger and fear.”

“Being alone, of no importance at home, left out of the family, especially the elderly who are not made to feel included or involved.”

Families

Although there is often an assumption that Asian family members generally look after each other, this group of respondents noted the need for positive family relationships and the fact that there could be all sorts of difficulties with families: constant conflicts, relationships, overwhelming daily responsibilities, all of which impacted on people’s mental health.

“Interaction between people can be good or bad. Family problems can be a trigger.”

“Abusive behaviour from others around you, not being valued or accepted.”

“Not coming to terms with a relationship difficulty; holding on to issues for a long time.”

Loss and Bereavement

The male participants in this group described the most difficulty in coping with the inevitable losses of increasing age and they felt that users were more likely to be suicidal.

“Loss of one’s partner; feeling abandoned”

“Attachments to people and things...so loss brings about lack of purpose in life.”

“There’s nobody to look after any more.”

“If you’re suffering alone it can cause depression, can lead to madness, loss of memory....helplessness.”

Gender Issues

Female members of the public reported that women were more inclined to mental health problems after marriage, with the demands and expectations placed on them due to culture and traditions.

“The joint family placing restrictions on the new wife about what to wear, going out etc leads to depression” This was said by an older woman who had been restricted in the prime of her life and now felt bitter about what she was not able to do when young.

On the other hand male participants were expected to take most of the responsibility of being the main breadwinner of the family. Loss of job then became a major cause of depression, anxiety and further mental health problems.

“Husband’s loss of role if he is not working.”

“Loss of job, negative thoughts, fear... financial difficulties”

Attitudes and awareness

Avoidance

It was observed by members of the public that generally the Gujarati-speaking community avoided mental health issues, that families hid these problems and often had little understanding of them.

“A family will not share, but hide away, or ignore and avoid the problem”

“They want to forget it, live in denial.”

“People do not necessarily disclose fully or debate about it.”

Shame and stigma

Part of this avoidance and denial, said members of the public, was to do with the community’s perception that it was incurable, genetic, and therefore shameful. It would therefore damage the marriage prospects of young people in the family.

“Its shameful in the community –don’t want others to know”

“Abnormal behaviour – the label carries a stigma.”

Ignorance of young people

Most of the elders felt that the young people of today did not behave as they should, and were very busy with their own lives. This could lead to lack of understanding, patronizing attitudes and negative assumptions about elders' capabilities.

"Youngsters are lost in their own world."

"Their attitude is – 'you take care of yourself'; 'you live as you see fit.'"

"It can feel very intimidating being restricted by younger members of the family when told not to open doors to strangers, not to use the gas stove, not to light prayer lamps etc."

Awareness and education

The group observed that the fact that mental illness was invisible, and perhaps intermittent, led to lack of awareness and understanding.

"Because you can't see it people are less sympathetic. It needs greater understanding. People do not know enough."

"We need more awareness of behavioural problems. Recognising it as an illness is very important."

"The community does not have the right attitude. They need to be educated and encouraged to respond."

They thought that people often concentrated more on attending to physical needs, rather than understanding emotional needs for general well-being. They believed there was a need for knowledge and education to bring about more awareness of mental ill health in the elderly.

INTERVIEWS WITH CARERS

The following questions were asked to 12 carers, all of older people with mental health problems. Some were spouses, some were adult children. Most of the carers who participated in this research had been caring for their relative with mental health problems for more than 5 years with one caring for almost 28 years.

WELL-BEING

How long have you been caring? Do you face any problems and difficulties?

All carers said they faced problems and half of the sample said that they faced many difficulties. The key difficulties identified in answers to this question were:

- Restrictions on going out
- Interpreting
- Health
- Finance
- Loss of friends

Restrictions on going out

Most of the carers assumed it was their total responsibility to look after their family member with mental ill health and although they did this from a strong sense of duty, they said they would prefer to have someone else share some of this responsibility. They did not know who or where to turn to for help and did not have much time or resources to look after their own well-being.

"I'm restricted in going out. I can only leave him alone for an hour."

"I feel trapped sometimes. I cannot leave the user on their own because there is a risk of them getting into danger. I have to be on the alert all the time. It can become stressful."

Interpreting

Those carers who came into the country without knowing any English still had problems accessing services which did not usually provide translation or interpreting. Moreover literature and information was in English and of no use.

"The local service has not been very supportive: the translation service is not available everywhere."

"All information for carers is in English. We aren't able to understand it."

"There is no translation or interpreting in the surgery. We have to go everywhere with someone. Its very stressful."

Health issues

Carers who had their own problems and were also struggling to look after the mentally ill person said that they were not being offered much help. They recognized that this could have long-term implications, such as ending up as a user themselves, although most appeared to be quite positive about their role and how they managed it. In fact, they said that the users were most appreciative of having such care.

“My own health problems have made it more difficult”

We’re not able to go out to functions or visit family as my wife has other physical problems like sciatica.”

“I lost my balance two or three years ago; I had difficulty walking before that.”

Finance

Most of the participants had migrated for various reasons to make a living in a strange country with little support, and yet were under pressure to support extended family who were still in another part of the world. This feeling of responsibility added to the burden of caring.

“Family problems – financial- being responsible for the joint family, even in India. I have to send money. They think you are working in a gold mine. Even my mother is not understanding.”

Loss of friends

We found that for most carers, the biggest difficulty was the isolation they faced in their role – they became so busy caring that they did not have any time for themselves or to pursue any outside activities.

“There’s no time for friends or social or leisure activities. I am too busy caring.”

“I missed friends and a social circle initially - it took time to make friends.”

“The culture is not supportive.”

How has [caring] affected you and your family?

Carers reported that the caring role had a number of consequences for them, the main ones being:

- Finance
- Restrictions on going out
- Health support
- Family support
- Lack of family support

Finance

Most carers were making the best of any financial set-back especially those who were full-time carers and we heard that this in itself could be a major cause of some mental health problems.

“Depression has been caused by our son’s actions – he’s out of a job, out of line. He drinks, smokes and gambles. He loses money and also suffers from depression and has been to rehab. My husband has had to pay his debts; it’s a big financial burden.”

Restrictions on going out

As mentioned above, this was felt by almost all the carers, and most were not even aware of the effect on their own well-being. Some accepted it, while others felt the isolation.

“Loss of independence”

“I cannot leave the house without my wife.”

“Because my husband does not go out, I don’t go out unless my sisters are there.”

“I feel isolated and alone, sitting home doing nothing – my mind is not active”.

Health support

Carers said that there was no clear cut route for getting the necessary professional help that they needed. Although they were playing a major role as a carer within the family, without a guide it was almost like finding their way in a dark forest.

“We had support from the clinic. The psychiatrist was very helpful and supportive - he has since left. Where else can we seek help?”

“It took almost two years to find out what is useful in the caring role. There are too many organizations to approach and conflicting advice given. I do a lot of research on the internet.”

Family support

Carers painted a mixed picture with regard to the impact of the caring role on other family members. In some cases, family members added to the stress of caring, instead of providing the support that was needed. Sometimes this was due to adult children moving away and sometimes due to unaware or even hostile relatives. In other cases the family members gave a great deal of help.

Almost all the older carers took full responsibility because they felt it was what was expected of them due to their culture and upbringing. They did the best they could under the circumstances, although some did feel that the responsibility should be shared, but were fearful of any consequences to the user if outside carers came in.

The older generation of carers generally accepted the responsibility of caring as a given and just got on with it, without expecting much.

“My husband is not a hindrance for me. Our sons are fully supportive and help.”

“Living alone with the user is OK as long as other family members are nearby.”

“We have to keep a constant watch on mother. She may get into danger – she leaves appliances turned on without knowing. We have to be alert at all times. It can be stressful.”

“I feel content – I can go out and leave my husband on his own every now and then.”

Parents reported that younger carers, who belonged to a different generation, were more focused around finding out the cause of problems and looking for better solutions, rather than passive acceptance.

“The children want to find out why its happening. Their thoughts are different.”

“Children working long hours – they’re not able to support older people. Yet parents depend on them entirely for visiting GP/going to hospital/shopping etc.”

Also sometimes the younger carers had to make more sacrifices, perhaps giving up jobs to take on the role of caring. In one case a young person in their twenties gave up education to be a carer of a parent, a role thrust upon them as the only solution.

“As a young person [I was] doing GCSE exams when Dad was in hospital with mental health problems and eventually passed away, it affected my performance and changed my life. I’m now working in the family business instead of doing further studies.”

Lack of family support

It was not necessarily the case that family support was forthcoming, for a number of reasons. Sometimes adult children had moved away and were less available.

“The children have not been fully responsible, sharing care, so at the end of the day we have to look after ourselves, as they have families to care for.”

“Our children are in different countries – Australia, USA.”

In other cases although family members did stay together there was conflict, especially where they were running the family business together:

“The family is useful only if you get on well with them.”

I had a possessive mother living in the same road, interfering. She didn’t like me working in the garden. My wife was constantly being taunted and told off for letting me do the chores and working in the garden. My sisters colluded with mother and were interfering too.”

*“Family business conflicts affected our relationships, causing a loss of intimacy. “
“It stopped us from doing better in life... I feel blocked with disappointments.”
And “My reason for attending carers’ groups – to get away from my wife.”*

Where would you go if you had a problem? Who would you turn to for help if you were distressed?

Most of the carers said that they turned to their GP or hospital for help, or else coped alone. A few resorted to carers’ groups. Carers felt there were very few avenues to turn to. They would attend prayer groups, read books, use the internet, use alternative medicines, or go to a natural health centre to find solutions to their difficulties.

What has helped you to cope? What has been useful for you?

- Keeping a positive attitude: *“Not remembering the past helps me. I just live in the present”*
“I keep my cool and take whatever comes in my life. I keep busy with work, watch TV or read papers.
- Professional support and information; carers’ meetings; centres for the user.
- Translation and interpreting
- Respite and breaks
- Transport
- Medication, herbal medicine for other health problems

Which activities do you participate in for your well being?

In response to this question carers listed a wide range of activities.

- All were involved in day-to-day activities in the home: housework, reading, writing, outings, shopping breaks, gardening, knitting.
- They listed hobbies: photography, music, playing bridge, watching Asian TV channels; watching sport.
- Exercise: walking, gym, dancing,
- Religion: prayers, meditation, yoga, mantras
- The internet - for socialising, for Indian music, for researching information
- Being with family and friends – trips together, looking after the grandchildren, talking to friends
- Classes, attending college

Do you have suggestions for well-being for carers like yourself?

Carers had many suggestions for themselves and for the users, from a range of personal supports (some listed above) to different sorts of professional help and information.

- *For the carers:* respite care, a break; activities and classes, support groups, centres and clubs for carers; training, religion, medication; a positive attitude; family help; translation services, transport.
- *For the mental health user:* befriending, counselling, day centres.

For the carers

Respite and breaks

Most carers interviewed, once encouraged, did feel they would like to get some help and only then would they be in a position to think about themselves or look for other options in life.

“More support- a break for shopping. I would prefer not to depend too much on my daughter if someone else can help.”

“If there was someone else to care for the user, I would be able to work part time.”

Most carers were keen to have a longer well-deserved break and were very appreciative of any such help they could get. This could be from a local service, or because they could afford to get away themselves.

“With respite care I manage to have breaks some nights or weekends to go to functions.”

“Visiting a health farm in India on a regular basis... I must get away and forget about things for a while”.

Activities and classes for the carer

“Resume computer classes.”

“Yoga, swimming, English classes; keep fit activities, shopping, Saturday clubs”.

“Meeting others, taking part in activities, doing photography again.”

“Keep fit classes”

Group support

The younger carers had more desire to be in touch with others and build a network, but generally were not really aware of what was available to them. Use of the internet was favoured also.

“I would like to know more about groups. I’m not aware of what is out there.”

“Formation of support groups.”

“Someone to talk to and meeting friends regularly.”

“Networking through on-line talking to other carers and expressing views.”

[It would be good to] have a blog on the local mental health charity website for carers to log on, suggest ideas etc."

Centres and clubs for carers

However, there were very few places that carers could resort to for themselves.

Asian Advice Centre

Going out to the local Car Park Centre

"Carers exchanging ideas with each other in various situations."

Professional support and training for the carer

Carers felt abandoned and isolated in their role with a lack of knowledge and training to enable them to better fulfill their role. Others were not even aware that they could seek help for themselves or get the right resources. However a number of them had a good idea about potential services, even though they could not access them. This varied from learning about how to better support the user, gaining information about the NHS(National Health Service) and benefits, to counselling.

"Carers should have the responsibility of knowing ... underlying problems, through greater awareness. They should understand what [mental illness] does to the person."

Training is important. Look at alternative ways of caring."

"I had to dig for information to get the disability allowance/ benefits, and go through so many questions. I would prefer guidelines in this respect."

"CBT(Cognitive Behavioural Therapy) is useful for understanding fear and anger."

Religion

This was a major factor in giving carers strength to cope. They mentioned yoga, prayers and mantras, meditation classes, actively practising their religion.

"Meditation and talks give a sense of peace."

"Religious books have really helped me."

Medication

Occasionally a carer became too overwhelmed and resorted to sleeping tablets, medication for depression or sought remedies for other physical problems.

"Herbal medicine for arthritis"

Attitudes to help one cope

Most carers displayed a positive attitude to their situation. They appeared quite calm and collected, expressed little in the way of resentment, grievances or complaints about their caring role.

“Not harbouring worries; being positive all the time.”

“Keep calm and getting on with work instead of complaining, and taking each day as it comes.”

“Being content with life; keeping busy.”

Family help

Most of the carers relied heavily on other family members to give them the necessary support and breaks, so that they could cope on a day-to-day basis, as well as on the company of friends and family.

“My daughter takes me out at weekends visiting every now and then.”

“Children caring and sharing are able to give the necessary breaks.”

“Close family and friends sharing the responsibility.”

Friends and relatives dropping in.

Translation and interpreting

Language limitations caused some restrictions in accessing services but some carers had accessed a Gujarati-speaking GP. There was also a strong reliance on using often busy younger family members to cope with issues.

“The doctor speaks Gujarati and there is an interpreting service in the hospital whenever we request it.”

“Family members are useful in helping with information in English.”

“Information is useful, but I would prefer to have it in Gujarati. I have to depend on other family members to translate.”

Transport

Difficulties of using public transport meant that in most cases carers had to depend on family members taking time off work to keep appointments, or they used a taxi card.

For the mental health service user

Befriending and counselling

For many carers the focus was still around getting help with the user more than anything for themselves. However they did want professional help that could really benefit them and carer at the same time. Befriending was cited by about half the carers as options which both supported them and gave the carer a break.

“I would like...someone to come during the day to keep her company, someone to talk to her, befriending.”

“Someone to give more time to the user, empower them to live life with less difficulty and be happier.”

Counselling too was seen as potentially helpful.

“Counselling for carers, and for the mentally ill person.”

"The doctor called all of us for family counselling at a local mental health clinic. Our sons came to understand better... It would be very useful if this service was given to us every 6 months.

Day centres

Carers did express some sense of relief that certain centres provided support and that they were able to use these regularly. The statutory mental health day centre, other local authority day centres for older people, and Asian day centres and clubs were all used.

"I take my wife to the day centre once a week, then I can go to the library."

Attend local yoga clinic once a week

"He attends Asian Day Centre on a Thursday."

Attend local Asian Friendship Clubs for people with learning disability

MENTAL ILLNESS

Which of the following symptoms contributes to the illness?

Memory loss, emotional distress, grieving, sadness/depression, anxiety, madness, disturbed behaviour, hallucinations, confusion, suicidal.

Carers agreed with all the above and added the following distressing symptoms :
Not liking to be questioned.

Feeling suicidal:

"He keeps on saying 'I will not be there tomorrow'."

"God is calling me"

"The sufferer can become suicidal. He also requested the doctor give him tablets to die."

Prefers quietness

"She is suffering, she keeps on cleaning."

Sobbing, crying loudly, shouting

"...During bereavement, he cries loudly, cannot control his emotions, especially (if he gets) depressing news."

Panic attacks, fear

No purpose in life,

Bad dreams

"Even in sleep the person is restless, shouting at night."

Not liking to be left alone

Talking to oneself

Seeing faces and hearing voices

"Delusions and hallucinations; the person suffering is disorientated."

What is your understanding of memory loss?

Is it age-related?

Here, it is interesting to note that some carers did believe that memory loss was age-related, unlike the users or members of the public in this research. Others believed it could happen at any time. Most did not perceive it to be a mental illness.

“Your body changes in old age – perhaps hormones are responsible.”

“Memory loss is nothing to do with mental illness- it’s a temporary phase.”

“It can happen at any time. Its more prominent in the over-fifties.”

My husband cannot remember the present but he has a good memory for the past.”

“It can be a process of getting older.”

“Its due to the effects of medication.”

What are your views on the caring role? Do you accept that it is your responsibility? Does your family support you?

All the carers we interviewed said that accepted their responsibility and attributed it to their Asian culture, religion and upbringing and expected their children to support them in the same way. They did however have a range of opinions when this question was explored further, from complete acceptance to resentment. Dependence on others was also a theme. The following were the main views expressed about responsibility:

- Karma
- Cultural expectations
- Full acceptance of responsibility
- Gradual or non-acceptance
- Carers’ dependence on others
- Users’ dependence on the carer

Karma

This was a powerful view expressed by some carers.

“I do not blame myself for the caring role, as I strongly believe in karma.”

“My husband may have looked after me in a past life, so I am caring for him in this life.”

Cultural expectations

“I don’t mind looking after my husband. It is my duty....as in my culture that is what is expected.”

“It’s my duty to look after my husband according to my culture. Upbringing is a key factor.”

Full acceptance of responsibility

Some carers did not allude to their upbringing or culture but still accepted full responsibility for their role.

"I believe its my responsibility as my other family members are married and have families of their own. So I accept full responsibility for caring for my mother."

"It is my full responsibility as my husband does not respond to caring from anyone else."

Gradual or non-acceptance

Some older carers admitted that they had previously felt resentful, but had now accepted their role, perhaps after years of caring.

"I used to feel 'Why me?' but I soon got over that when I came to know about so many others suffering."

"I have been caring since 1965. Although I did not like it initially I have learned how to cope."

Others continued to feel aggrieved:

"I have no time for myself."

"Why only me?"

Carers' dependence on others

"I'm losing my independence... though the family helps out every now and then."

"I haven't really thought about what will happen when I get married, which is likely to be soon."

"In an emergency I call my sister or my friend."

Users' dependence on the carer

"The user does not like to be left alone."

"He is not able to stay alone or go anywhere else without me."

"I cannot go out when I want to, or I can only go out for a short while."

What do you understand/your community/family think about mental illness/problems?

Most of the carers did feel that there was a lack of awareness and non-acceptance from the community generally. There were issues of being labeled and sometimes ill-treated. They also felt that often the younger generation wanted to live independently and not support them.

Respondents' views were divided about what they believed the community thought about mental illness. The predominant view was that the community stigmatized it, with some harsh labeling. Negative family reactions were also significant.

- Negative community views and stigma
- Positive community views
- Family reactions
- Medication

Negative community views

Some thought that the community perspective ranged from outright rejection to uncertainty on how to react.

“The community thinking is religious – nobody wants to accept mental illness”

“People from the community don’t really come to visit you, but... are Ok to see you if you visit or are attending community functions.”

“The community is usually more interested in gossiping; there’s not much awareness. You have to keep reminding them.”

Stigma and labelling were common:

“They never treat it seriously. They class illness as madness.”

“They use terms like ‘powli’¹⁹ and ‘aardhu’²⁰

“Seventy percent are not aware of mental health issues. They label my wife as mad and think she should be in an asylum.”

Positive community views

Nevertheless other carers reported that community members were ready to help and were accepting.

“Most of them are friendly and supportive. Everyone has their problems.”

“Most people are friendly and accepting. You don’t really feel a stigma.”

Family reactions

Family reactions also varied, with some carers feeling their adult children, from a British culture, were less supportive.

“Sometimes family support is not evident. There is no help or caring attitude”.

“Children do not understand, they need to know why it happens.”

“Children care in different ways. Being brought up in a different culture in the UK, (our view is) different from how they see caring.”

“There is a lack of understanding and knowledge...training is needed.”

However they also noted with feeling that in-laws constituted a longstanding source of difficulty.

“Families are the biggest problem in the Indian community.... Daughter-in-law gets demands from in-laws. They try to take credit for everything, are powerful, not prepared to listen....many suffer silently without any hope, get depressed and end up with physical problems.”

¹⁹ lowest value in Indian currency

²⁰ of half value

Medication

People spoke about medication in relation to mental illness and the uncertainty of its efficacy or about the speed of it working.

“You have to be careful with medication... its only effective after a few months, when you notice the difference in the person.”

“Its very hard to assess the benefits of medication. You don’t know what time frame you are working within to observe any differences.”

“Ayurvedic²¹ medication is too slow a process, especially if the person is too impatient. I’m not sure about Western medication.”

What do you think causes it?

Seven choices were offered: Karma, magic, God, life events, old age, punishment and side effects of medication.

Themes

- Physical causes
- Emotional causes
- Spiritual causes

Physical causes

Carers reported that they understood it was caused by a wide range of physical causes from brain chemistry, ill health, genes to drugs and alcohol.

“In the genes. Mother also suffered and it was evident at an early age.”

“A stroke can cause physical disability, which brings about mental health problems.”

“Not being able to control an incontinence problem.”

Emotional causes

Family difficulties – loss, bereavement, trauma – were seen as relevant, along with not being able to manage certain feelings – frustration, fear, negative thinking.

“Separation from the family; multiple deaths in the family in a short space of time.”

“Negative thinking – fear and feeling threatened.”

“Mental illness is on the increase due to people’s expectations.”

“Being traumatized by life events – mugging in Kenya with knives.”

There were mixed views about whether it was age-related.

“Depression can be triggered by anything at any time to anybody. Its more of a problem for the over- fifties.”

“Mental illness is not due to old age.”

²¹ Indian herbal medication based on holistic principles/life study.

Spiritual causes

"We suffer because of our own karma."

My karma is responsible for me being a carer."

All participants believed in a number of causes: eg karma, evil spirits, punishment for bad deeds and medication side effects for instance. Others attributed suffering to punishment, magic, old age and even God in one case.

The idea of punishment was quoted by both Hindus/Jains and Muslims. Hindus and Jains believed that mental health suffering could be part of their karma through many lifetimes, whereas Muslims believed it was more to do with punishment in this lifetime. Most of them believed in evil spirits; Respondents from all three religious groups also cited life events and side effects of medication as potential causes.

DISCUSSION OF FINDINGS

We interviewed seventeen service users, twelve carers and twenty one members of the public. There was considerable overlap of views between the three groups. These are summarised below, bearing in mind the key objectives of the Government's document *Delivering Race Equality in Mental Health Care*, relevant for all three groups of participants who were interviewed. The five key themes highlighted in that document are:

1. Challenging Stigma and Fear
2. Equality of Access
3. Cultural Sensitivity
4. Improvement in Communication and Information
5. Choice of Culturally Appropriate Services/Therapies

These link closely with the findings and the concerns expressed by all three groups around mental health services for older adults. Moreover while this report addresses the needs of older adults, the recommendations apply equally to services for people under 60, both users and carers, as many services in both the over and under 60 age groups have been identified as ethnically insensitive.

FACTORS CONTRIBUTING TO MENTAL ILL-HEALTH

Changes in lifestyle and culture

First we give an outline of the issues which participants felt they had to deal with when they first arrived in the UK, many of which the users considered had contributed to mental ill-health, either their own, those of their loved ones, or people they knew in the community.

Migration

The majority of users of mental health services were born in India or in East Africa (Kenya, Tanzania or Uganda) and have been living in U.K. for at least 5 years. Most had been here for upwards of 25 years. Most of the participants had migrated and some had come to the UK as refugees and had made a living with little support. 70% of the users claimed their illness started after coming to this country. Most of the users claimed they had great difficulty in adjusting to the climate, culture and life-style in this country. All of them had faced hardships in housing, finance, and employment. Many felt very isolated and excluded due to the language barriers, the strangeness of the culture, unfamiliar food, and people too busy to greet each other.

Members of the public also cited the negative impact of migration as contributing to mental distress. They highlighted the losses experienced by people due to

having to come to the UK – loss of work, status, family and friends left behind, loss of a comfortable lifestyle, even a purpose in life. The long-term ill-effects of migration on individuals cannot be underestimated.

Loss

Alongside the losses experienced due to migration, bereavement due to the death of one or more close family members and other losses were viewed as key factors contributing to mental ill health. As well as miscarriage and infertility, loss of employment in this country were all very painful for people. Loss of independence and the loss of support of family members were also relevant, but as consequences of mental ill health rather than causes of it. Loss of physical health due to age was common among all three groups and added to the distress levels of service users. A number, mainly men, expressed suicidal ideation, feeling that life had lost all meaning for them. Members of the public confirmed the serious impact of loss and that this was more difficult for men.

Loss of role for men - work

Male participants were expected to take most of the responsibility of being the main breadwinner of the family. Loss of job or redundancy became the major cause of depression/anxiety and further mental health problems for some users. One male participant claimed that he started having the problems after losing his job and he did not receive any support from the medical profession or his community in the earlier stages to help him re-engage in any employment, recreational or social activities. It was only when he commenced meditation (Vipaassana) that he recovered from some of the depression and loneliness.

We also found that some of the male participants who were at home due to unemployment in this country felt shamed by their wives working. This could be a contributing factor to their mental health problems. In the Asian culture in Africa and the Indian sub-continent, it used to be customary that the male members of the household went to work and the wives looked after the household. However although this practice/custom no longer applies in those countries, the men interviewed still felt bound by it.

Financial difficulties

Those participants who had been forced to leave Uganda or Kenya faced serious financial hardship due to having to leave everything behind when they fled. Upon arrival in the UK some had to borrow money, others had legal expenses, or could not get jobs commensurate with those they had previously held. One participant had not recovered from the financial difficulties he had experienced in Africa and later financial troubles in this country. Another described how years-long litigation with relatives had taken all savings. Some older carers were also supporting mentally ill adult children financially.

A major pressure was that some respondents from all three groups said they either had been or were still under pressure to financially support family members

still residing abroad. This added to the burden they had caring for themselves and their family here under difficult circumstances, whilst feeling responsible for those in other countries who depended on them. Some felt that their dependent relatives had no appreciation or understanding of their sacrifices or their current difficult circumstances.

Non-specific emotional causes

Carers cited such varied causes as negative thinking, trauma, frustration, fear and anxiety. Most users and all members of the public believed life events such as a husband having an affair, long-term caring, lifestyle changes, and ill treatment in marriage were triggers. Some also believed that the customs and rituals observed during their childhood had affected them later on in their life and that past events contributed to current insecurities. One carer expressed a view that mental health problems of the user were due to upbringing and hereditary factors.

Family pressures on women

Female participants were more inclined to mental health problems following marriage, with the demands and expectations placed on them due to culture, belief and traditions. A number of female participants claimed ill treatment and interference by their mothers-in-law had contributed to their mental health problems.

Some of the female participants also claimed that living within a large family in this country has contributed to their problems. While extended families often stayed together in the one household, there were frequently pressures to conform and there was not necessarily good support.

The joint family placing restrictions on the new wife about what to wear, going out etc had led to depression for some. A user who experienced the above restrictions in the prime of her life still felt bitter about what she had not been able to do when young.

Physical causes

Some members of the public and carers stated that they thought mental illness was a hereditary defect, while most of them believed that physical health difficulties such as inactivity, or physical illness such as a stroke could cause mental illness. Some carers too believed in physical causes such as alcohol, drugs or disturbed brain chemistry.

It was noted that medication was also perceived by some users and by all members of the public to be a contributory factor to mental health problems. Some thought side effects of medicine for physical conditions could lead to mental health problems, and others believed that side effects of psychiatric medication were sometimes wrongly attributed to the mental illness.

Religious beliefs

Hand in hand with an understanding that life events and stresses could cause and precipitate mental illness, were religious beliefs about the reasons for one being afflicted. Karma and punishment, based on Hindu religious belief systems, were perceived to be a major reason for mental illness among most members of the public and among carers. The majority of these Hindu participants believed past and present karma to be the main cause, being punishment for past bad deeds or wickedness. Users' beliefs, on the other hand, related far more to stresses and life events.

They also felt total responsibility for their lot in life due to their karma and that they had to undergo their punishment in this lifetime. This creates a fatalistic attitude, perhaps making it difficult to change their perception and gear them towards mental well-being. 'Karma' according to the Hindu faith is somewhat different to what Muslims believe. To the latter, bad deeds in this lifetime lead to the need to undergo punishment now, as they do not believe in reincarnation. Amongst the small sample of those interviewed from the Muslim faith, there was also a strong belief in black magic as a cause of suffering, and for which nothing could be done. We cannot say if this was representative of this group.

CAUSES OF MEMORY LOSS

All participants accepted that memory loss was a mental problem, in the sense that it was a difficulty with the mind. Users and members of the public had mixed views about the causes of dementia and memory loss. Many users related loss of memory to stress and worry, causing preoccupation, and emotional shock or distress such as bereavement or other difficult life events. Others thought it was due to physical ill health such as a stroke or the menopause, after-effects of an accident or a side effect of medication.

Most users and about half of the members of the public, believing it to be stress-related, thought it could occur at any age and cited as evidence very elderly people with excellent memories. Some members of the public believed it was one's karma and could occur at any age, even from birth. Carers on the other hand tended to believe that memory loss was a physical deterioration with increasing age and therefore not a mental illness. Keeping the mind active therefore was seen to be important as a preventative measure.

PRESSURES ON CARERS

Of the twelve carers interviewed, nine had been caring for over six years and five of those for thirteen years or more, and one for almost forty five years. Only three had been caring for three years or less. It was clear that they had a great deal of experience to draw on and described many difficulties as a result of this.

Older carers

Age was a factor in how people accepted the caring role. The elderly group of carers accepted the responsibility of caring as given and as their duty, and just got on with it, without expecting much. As most had finished work before taking on the role of caring, they made an easier adjustment than younger people.

Older carers were also facing serious health problems such as diabetes, high blood pressure, cancer, arthritis, memory loss and their own mental health issues. Family pressures could increase emotional difficulties. These are addressed in more detail below. Nevertheless, all older carers were accepting of their role and thought little of their own well-being. Some stated this was due to their culture and upbringing, some referred to this as their karma.

In the long term, our fear is that the stress and strain of caring may bring about mental health issues in the carers themselves as we noted in a case where a previous carer within the family was facing mental health problems now but was not seeking nor had any awareness of outside help.

Physical restrictions

Older carers described being seriously limited by the practical restrictions of needing to remain with the user all the time. They felt unable to leave the person for any period, and some said they felt trapped as a result. It was unclear whether this was due to the seriousness of the user's mental or physical ill health and risk issues or because of a strong sense of duty. They had travel problems too, being unable to use public transport with the user and needing taxis or having to rely on other family members, usually adult children to take them for GP appointments or hospital visits.

Younger carers

In other cases, younger adult carers found themselves in roles that had been thrust upon them, looking after their parents, as there was no other way to deal with the situation. These belonged to a different generation and their thoughts were more focussed around finding out the causes of problems and looking for better solutions, rather than passive acceptance.

Stress of the caring role

Some carers were resentful of the ties and loss of independence, that their partner did not want to be left alone. In addition the caring role itself was seen as a factor in mental distress. While most carers appeared to be quite positive about their role and how they managed it, for some the strain of caring brought its own issues. In some cases living in a joint family added to the stress of caring, instead of providing the support that was needed. Sometimes a previous carer within the

family was now facing their own mental health problems, but was not seeking help and had no awareness of possible outside support.

Isolation

For most carers the most serious difficulty was the isolation they experienced, partly because they were so occupied with their role that they had no time for external pursuits or for friends. They also cited the lack of the support and perceived stigma within the community as factors in their remaining isolated.

Family Pressures

Isolation and loss of external social contacts for carers meant that their family relationships were of paramount importance. We obtained a complex picture of how families cope with mental ill health and the responsibility of caring. The stereotype of an extended family living together, offering mutual support was not borne out by the evidence in many cases but in others, family support was powerful and significant. It is perhaps an indication of this complex picture that only nine of the seventeen users stated that they would turn to their families if they were distressed.

A number of the difficulties which users and carers described in their families were linked to intergenerational conflicts or longstanding disagreements between in-laws. Problems to do with possessive mothers, controlling and even abusive mothers-in-law, domineering spouses and interfering relatives were regularly expressed. Many of these conflicts were longstanding or in the past and were felt to have significantly contributed or even caused mental illness, so were still recalled with feeling. Some felt that their adult children now had mental health problems as a result of the lack of support from relatives.

Other causes of conflict had arisen in relation to different members of an extended family going into business together and this not working out. While these were not direct pressures on caring, they added to stress and, at times, caused bitterness, leading to loss of support. Some carers also felt this contributed to their own mental distress.

Older carers also gave a range of views about whether or not their adult children were supportive. Children moved away or were working full time and had less than ideal time to give to assisting their parents. Some had moved abroad to Australia or the USA. Some carers appreciated the reasons for this, and accepted that their children had been brought up in a cultural environment which considered caring differently from themselves. Others were resentful and perceived their children as not accepting responsibility and inappropriately wanting greater independence.

Other carers stated that their children were fully supportive, taking them to appointments, relieving them of minding responsibilities. Most carers relied

heavily on, sometimes several, family members to give them a break. Several users reported that family members were understanding of their anger as a manifestation of their mental illness. In one case a young person made significant sacrifices, for instance giving up educational opportunities to care for their mentally unwell parent or in another case, giving up a job.

STIGMA SURROUNDING MENTAL ILLNESS

All the three groups of participants identified a serious lack of awareness of mental health problems in their community with significant stigma in the family and the community, although they said it was less severe in the UK than the Indian sub-continent and East Africa. The following were the major effects of stigma and prejudice.

Negative effects on users and carers

The majority of the users claimed they did not trust their friends, relatives or their community in discussing their problems for several reasons: lack of community awareness; lack of interest by others; shame and discomfort in users and carers; lack of trust and fear that others would gossip or label them. This view was shared by most of the carers and general public. Some participants mentioned that having a family member with mental health problems would affect children's marriage prospects, so for this reason they did not mix with their community.

Perhaps surprisingly then, users were eager to talk about their experiences and often over-ran the interview time, so much did they have to say. Some also found the research therapeutic in itself, having spoken about such matters for the first time to anybody else in their life.

Labelling

Stigmatising pejorative labelling was identified as a common concern, even within some local professional services. Negative expressions such as '*paaga*²²', '*powli*' and '*aardhu*' were recalled by some users and members of the public. There was thought to be little understanding of actual mental illness, with beliefs that mentally ill people were mad and should be locked away. The focus group also came up with other terms such as: Vichitra,²³ khasi gayu chhe²⁴ and chakram²⁵

Members of the public said that young people were more likely to be worried about risks that users posed and were making assumptions about a relative's mental distress on the basis of age alone. Some elders were being forbidden to answer the door to strangers, or use the kitchen, being thought to be at risk

²² Mad

²³ Abnormal

²⁴ out of one's mind

²⁵ Mad, spinning mind

because of forgetfulness. At times this was realistic, but at other times it was perceived as ageist by the participants.

Perceptions of community views

Most users and carers thought that their community had little awareness of mental illness, or about how to deal with individuals who experienced mental health problems. Some felt the community was accepting but ignorant, while others thought members had no time for them and had no understanding. Members of the public who were interviewed also thought this about their community: non-recognition, avoidance and lack of sympathy were believed to be typical reactions. They tended to blame their community leaders for these attitudes. At the same time some indicated leaders were sympathetic and would like to offer support to people with mental health issues, especially if they were more knowledgeable.

Users and carers felt that community members gossiped and spread rumours about them. Mental illness was viewed as shameful. One member of the public observed that families and users knew they would be labelled if they spoke about their problems, so did not admit to them. Thus avoidance and denial were seen as usual reactions to mental illness for obvious reasons. Carers reported that the community had concerns about people's behaviour in public, but recognised that this was because people were uncomfortable and did not know how to respond.

Nevertheless some carers said that they found their community to be supportive, that there was no stigma attached to mental distress and that people were willing to help. Moreover members of the public stated to us that although they did not know any users, they would like to help and it seems that the interviewing process alone was sufficient to raise some awareness.

Perceptions of appropriate roles / gender role distinctions

Both users and carers found that there was community stereotyping with respect to the caring role. Some carers said that as men, their families had disparaged the fact that they undertook so-called 'female' tasks to support their unwell wives. On the other hand, some women said that their husbands had not given any help at all and expected them to continue do all household tasks even though they had serious mental health difficulties. One was relying on her children as her husband spent much of his time abroad. As stated above, men were expected to be the breadwinners, so loss of job was a major stigma and hence could be a cause of depression and anxiety.

WHAT PEOPLE FIND HELPFUL

What people have found useful

Users and carers were most resourceful in utilising a wide variety of means to support themselves with their mental health and in their caring role. Some of these were self-generated and some were part of formal service delivery.

Social activities were valued, both in the home and outside, as well as outings and longer trips. Several people went abroad several times a year. Others kept physically and mentally active with exercises, classes and hobbies. TV and the internet

Motivation and attitude

Both users and carers felt it was extremely important to retain a positive attitude. Ways of doing this varied from keeping occupied to not dwelling on the past. Willpower and determination were perceived to be important. It was clear that other activities and pursuits and religious beliefs and support helped them in this.

Day centres and professional help

A number of users attended a mental health or elders' day centre or a local community group or club. Some of these were Asian-specific and valued. While the non-Asian centres were also appreciated, all users complained about the poor awareness of cultural and dietary needs and the lack of Asian food and cultural activities in the statutory centres. There were also requests for Asian-only residential accommodation to cater for users' requirements.

All users saw their GP regularly and would call upon him/her if they needed help. Most used Western medicines but a few also utilised Indian or Ayurvedic medication. It was however perceived to be slow to take effect and not so readily available on the NHS and not really recognized by the medical profession. Counselling services and befriending were also mentioned. Very few carers (three) attended support groups and both users and carers said they would value these for themselves. Users however differed in whether they wanted to be with others who were unwell or not, some preferring different sorts of people together. Choice is essential therefore.

Religious observance

Most users, carers and members of the public valued and found great comfort in their religious beliefs and practice: prayers and rituals, meditation, yoga, and sacred literature, either at home, in small groups or going to the temple. However some people disapproved of 'empty' rituals and others felt that such groups were excluding and not welcoming of individuals with mental health issues. How or whether such religious observance should be included in statutory day support is a question to be considered in the light of users' wishes.

What people would like in the way of help - ethnically sensitive services

All the above were cited as important and it was felt they should be extended. All users and carers wanted easier access to Gujarati-speaking professionals, as well as culturally sensitive day support and facilities. Asian-specific befriending and talking therapies were requested. While there were some Asian day centres for users, there were very few places that carers could go for mutual support. This is addressed in more detail below. They reported that more opportunities for respite and short breaks would allow them time for themselves and relieve them of some responsibility for a period.

What people would like - awareness and training

While carers tended to say that they sought improved services for the user, most also said that they wanted more group support for themselves, and opportunities to share experiences. Younger carers in particular wished to have contact with people in a similar position. They also thought that on-line supports and a blog would offer ideas, suggestions and contact.

Carers and users alike wanted training - to help in caring, and information about benefits and about the NHS, for example. Both groups noted that mental illness was invisible, so did not arouse sympathy. They felt that education to raise awareness among community groups and individuals would help people to understand the issues and improve attitudes towards mental ill health. It was interesting that this research has, of itself, raised the level of awareness among the community and religious groups approached and some of these have suggested that they would like to increase their knowledge and to offer more support.

EQUALITY OF ACCESS, CULTURAL SENSITIVITY OF SERVICES, COMMUNICATION AND INFORMATION
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Equality of access is linked to many factors, but partly related to the cultural sensitivity or cultural specificity of services and good information about them. We will deal with all these issues under one heading as they interlink closely.

The majority of the users and carers did not access services for various reasons when they arrived in this country and some were still not doing so. Some of the reasons were clear, but this is something we feel needs to be explored further. Some of the reasons given were:

Dislike of 'charity'

Their culture and upbringing led them to feel this would be living on charity, something they had never done, having worked all their lives in the countries they came from. As most of the participants had been living in a close-knit community, there was also a fear of claiming benefits and services due to shame and

embarrassment. It had taken time for them to change their views to access services. Others still did not know all their rights.

Transport

Access was also limited by transport availability, with many users stating they were dependent on their partners or children to escort them to their GP, clinics and hospital. They believed that if they had better access to transport, the professionals might be able to see them more regularly.

Publicity and Language issues

Some carers had no knowledge of services available for them and they all felt that the services were not being publicised or advertised by the local council.

We noted from our interviews that almost all the participants preferred speaking in Gujarati, as this was their first language, although many of the participants could speak and understand English. Almost all participants in the three groups confirmed that the information for users and carers is either not available in Gujarati, or is written in such formal academic language (rather than in everyday speech) that it is barely comprehensible, all of which severely limited their access to information. Finally, understanding spoken English did not necessarily indicate that a person was fluent in reading it.

As there was no translation service available in most GP surgeries, we found the majority of users were relying on their partners and children for translation and interpreting in GP surgeries, and in hospital clinics. Others registered themselves with a surgery that had Asian doctors. All users and carers said that communication with service providers could be improved by providing Gujarati-speaking staff with good cultural awareness.

It is interesting to note that it is unclear from our findings whether participants would prefer to have a family member translate for them because of not wanting an external member of the community to know about their mental health, or whether they would prefer a stranger so that their issues would be kept confidential to the user. Our general perception is that most Asian elderly people would prefer and trust their own family member to translate for them, although it is uncertain whether they would share all their issues with them. This needs to be explored in future.

The government's Delivering Race Equality in Mental Health Care strategy outlines 3 main building blocks for improving the service for people from Black and Minority Ethnic backgrounds. These building blocks include the development of more culturally appropriate services. Our response to this is outlined below with discussion on the relevant points from this community engagement research.

CHOICE OF CULTURALLY APPROPRIATE SERVICES/THERAPIES

Alternative therapies

Although the majority of the users believed in taking alternative therapies such as Ayurvedic, herbal, homeopathic and other medicines, none of them except one were currently taking them, although some had tried them earlier in life. They felt that these took longer for benefits to be achieved. Some of the carers were currently taking them and finding benefits.

Members of the public were in favour of taking alternative medication and they felt that the Western medical profession should encourage this practice, as they believed it had minimal side effects. They also would like a range of talking therapies which would be culturally sensitive, listening and support being valued by users and carers alike.

Lack of cultural awareness by professionals

Another factor which would make a service accessible would be a good understanding of people's background, heritage and attitudes. Some of the participants claimed the services/treatments did not meet their cultural needs and were inappropriate, and blamed the medical profession and service providers for their lack of cultural awareness. A few professionals had been explicitly stigmatizing.

This is a major training issue which needs to be addressed. In particular some users had received counselling sessions in the past but had not benefited from them, possibly because the counsellor either did not understand their culture, or failed to consider the family unit as a model which may have been useful in an extended family household.

Cultural appropriateness of services in day centres

The majority of users were attending day centres regularly but felt that some culturally appropriate activities such as yoga, meditation and prayers were not provided regularly. There needs to be a discussion between service users and providers about whether prayers and religious observance are appropriate in a statutory day centre, and users then being made aware of the reasons for the decision.

While the majority of users and carers enjoyed watching the Asian TV channels at home, two users in supported housing regretted not having cable access to an Asian TV channel in their centre. This would be an inexpensive and easy way of providing culturally sensitive options for Asian users.

Meals

In particular many users claimed they were not provided with proper Asian meals in day centres. There was not only no provision, but no awareness of dietary requirements, and an assumption that users would adapt. Three users who attended a particular day centre claimed they brought their meals from home as the meals provided were not proper vegetarian Asian meals, being cooked in the same kitchen with non-vegetarian meals.

Mental health professionals linked to this research are aware that this has been a highlighted issue for many years and yet has never been properly addressed by most statutory services. Given the large Asian community in Harrow, and the length of time they have lived in the UK, this seems to us to be bordering on institutional racism.

RECOMMENDATIONS

This research has highlighted the need to do significant work to achieve equitable access to mental health services for older Gujarati-speaking Asian adults in Harrow. In addition we believe the recommendations apply equally to other age groups and the general thrust and thinking should be applied to considering the needs of other South Asian and Black and minority ethnic groups in the borough. The recommendations are linked to national policy and are targeted at local decision makers.

Recommendation 1:

All Harrow mental health services should recognize and offer Gujarati-specific service options.

Specifically to:

1.1 Ensure information support and signposting, with Gujarati user-friendly translations of information leaflets, signage for services, and for benefits.

This will include Harrow Primary Care Trust, Central and North West London Foundation Trust, Harrow Council and relevant voluntary sector organisations. By user-friendly we mean translation into non-academic spoken language. The local Harrow UKAWC (UK Asian Women's Conference) Translation and Interpreting Service has a budget to support mental health users, which may be used for leaflet translation.

1.2 Improve meals in non-Asian day centres to offer vegetarian, separately cooked, Asian food. Lack of awareness of the dietary requirements of different religious and cultural groups can be remedied by training, with Asian chefs advising non-Asian providers.

1.3 Have culturally relevant activities and pursuits as standard options in day centres, the hospital and the voluntary sector. Activities such as yoga are offered in some centres, and this can be expanded, and other ideas from service users brought in.

1.4 Support choice for service users. It is clear that some users wish to be in groups of people with common needs, while others prefer to be with people from different backgrounds and with different issues.

"We must pay greater attention to meeting the service needs of people from ethnic minorities. This will help us to meet the standards both for improved services and health outcomes ..." (Equalities and Human Rights Scheme Appendix 7; Sir Nigel Crisp's 10 Point Plan, 2004)

"Fair treatment by local services", a target to tackle Exclusion. (Draft Local Area Agreement, Harrow Council 2008)

Recommendation 2:
The services should pro-actively recruit Gujarati-speaking workers.

Specifically to:

- 2.1 **HR (Human Resources) departments in Harrow Council and in CNWL (Central and North West London) FoundationTrust should work to develop a more balanced workforce**, particularly those who work directly with older Gujarati-speaking Asian adults and their carers in non-ethnically-specific settings.
- 2.2 **Each generic day centre should have at least one Gujarati –speaking worker.** It is in these centres that users feel their cultural needs are not understood or met, and often prefer to not attend for this reason.
- 2.3 **A Gujarati-speaking worker should be recruited to the Older Adults Mental Health service to outreach to families and to community groups.** The need for a worker whose first language is Gujarati is of paramount importance for older adults, whose command of English may be poor and whose awareness of local service delivery choices is limited.

“The workforce in mental health services should be ethnically diverse. Where appropriate, active steps should be taken to recruit, train and promote black and minority ethnic staff.” (Delivering Race Equality in Mental Health Care, page 25)

Sir Nigel Crisp’s 10-point plan also includes the need to improve training, development and career opportunities for all staff in race equality issues, with the need to: “Develop more entry points for people from ethnic minorities to join the NHS and take up training. Improve access for BME staff to the full range of development programmes, support networks and professional training.”

“Respecting Diversity. Working in partnership with service users, carers, families and colleagues to provide care and interventions that not only make a positive difference but also do so in ways that respect and value diversity.” (The Ten Essential Shared Capabilities: A framework for the whole of the mental health workforce, Department of Health 2004)

Recommendation 3:

To promote capacity building in the local communities, work should be undertaken there to improve the information available, create positive links between the cultural needs of the Gujarati-speaking Asian elders and service providers.

Specifically to:

3.1 Encourage the Primary Care Trust to identify a Community Development Worker post for older adults. Outreach by such a post-holder will capacity-build local communities by addressing stigma and ignorance, highlighted in our findings as major issues. The CDW role was identified as part of the requirement to improve services to BME groups in *Delivering Race Equality*. The goodwill developed in community groups in the course of this research can be harnessed to help the communities take positive action, with further support recommended below

3.2 Local Gujarati speaking communities/groups/clubs should be empowered by training to support voluntary 'Community Champions'. These will be able to act as channels to communicate accurate and up-to-date information on mental health services to their members and also encourage integration of service users and their carers into their activities and groups.

"Challenging Inequality: Addressing the causes and consequences of stigma, discrimination, social inequality exclusion on service users, carers and mental health services." (The Ten essential Shared Capabilities, DH 2004)

"Community Development – to build on the inherent strengths in and with the BME communities themselves...reclaim the responsibility and ownership for their health and social care." (Community Development Workers for Black and Minority Ethnic Communities. DH 2004)

Recommendation 4:

Provide training opportunities to service users and carers who have identified that they would value much more information, knowledge and awareness of mental health issues.

4.1 Expand the Expert Patients Scheme, run by the Primary Care Trust, which now includes mental health users. It can be further developed to include older Gujarati-speaking service users. This could link with training programmes currently offered to service users by Mind in Harrow and by Harrow User Group. These users would be both a resource and a support to their peers.

4.2 Carers' Education. Harrow Carers' Centre has offered training for carers of people with mental health problems under 65, and is currently revising this. With the employment of a new Gujarati-speaking Care Support worker, this is an opportune time to include a package for older Gujarati carers.

4.3 User support groups with professionals. Establish education and support groups on such topics as anxiety and depression, run by a Gujarati-speaking worker from, for example, Older Adults Psychology Services, in community venues.

Encourage appropriately qualified leaders from ethnic minorities in health and other sectors to consider and apply for executive positions. Link with borough Community development Strategy, Local Area agreement.

Recommendation 5:

Gujarati speaking elderly communities and service users should be involved in monitoring and reviewing the services, and in the development of new ways of reaching those in need. Service user involvement in monitoring of mental health services is still in its infancy in Harrow, but with discussions starting in CNWL Trust, and with workstreams and targets identified in Harrow Council's new Adult and Housing Transformation Programme Plan (pp 13-14), this is an ideal time to be planning structures for full inclusion of Gujarati-speaking older adults.

“Greater involvement of service users, carers and representative organizations, including under-represented sections in the BME population, in the planning of future services...” (Draft London Borough of Harrow Adult and Housing Transformation Programme Plan, 2008-11).

This is in line with the vision set out in *Delivering Race Equality*, which states: *a more active role for BME communities and BME service users in the training of professionals, in the development of mental health policy, and in the planning and provision of services.*

AUTHORS' REFLECTIONS

The research was carried out within a short time-scale, soon after the first two training workshops on Research Methods in June/July 2007. Interviews did not start till 21st September 2007 and finished on 8th January 2008 during which time, 50 interviews (29 1:1 interviews and five focus groups) were conducted. In spite of the time lost due to Ramadhan, Diwali, Eid and Christmas festivals, we feel we achieved a maximum number of participants. We were well supported by Joanna, our support worker from UCLan, and by the tutors at the training workshops we attended in London. We also had good support from the Steering Committee comprising professionals from the medical profession and service providers which met every month.

As members of a team which came from different backgrounds, we felt that we worked well together, and formed a good partnership which we hope we can work together in future to implement the recommendations and also work with the community.

Several factors affected the results: first we did not ask each group of participants identical questions within the main themes, so detailed responses differed between users and carers. Focus group questions to members of the public were of necessity different from individual ones and so gathered somewhat different information. Moreover the users were clearly greatly relieved to speak, and their responses to some questions spilled over into others. They provided far more information than was required by the questions. At times participants in all groups either did not answer the question asked, or responded with different, although still informative replies. With hindsight we would have asked some of the questions in a rather different way.

Third, most of the research interviews were conducted in Gujarati, transcribed and simultaneously translated into English, sometimes in shorthand, and then typed up in English. There were thus four or even five stages to recording the raw data, which must have resulted in some adaptations and changes to what respondents said, however minor.

We managed to include most sections of Gujarati speaking elders living in Harrow, except the Zoroastrian group. However, we would have included them in our research if their clubs/groups were listed in the Harrow Council listing of 'Services in Harrow specifically for older adults from black and minority ethnic communities'. Moreover it took a long time to gather Muslim respondents, partly due to religious observance and festivals, and we are aware that the views of this group have not been well represented. We suggest that these groups should be included in further similar research in future.

Confidentiality

Our initial thoughts before approaching our participants were that we might obtain very restricted views and opinions from them as the subject we were discussing was very sensitive in the South Asian community and we might not be able to access information fully. However we were proved wrong from the very first interview conducted. We are very grateful to all the participants who were very supportive and helpful in giving us the information. It was interesting to note that the user participants were very comfortable in sharing all their issues and concerns with us in spite of not knowing us beforehand and most importantly, fully trusted us with confidential material. We also felt that they wanted more time to be allocated for the interview. We suggest that this point should be taken into account in any future research. One participant while speaking to one of the researchers said she felt very good in sharing her issues and concerns with us during the interview and claimed that this was the first time she had shared her experience with anyone.

Nevertheless due to the small size of the sample, the close-knit nature of the local community we interviewed and the acknowledged stigma surrounding mental health, we have anonymised individual examples as far as possible without losing the points being made. Sometimes examples in the Results section and Discussion may seem rather general as a result of this.

Finally, we found this research work very satisfying and rewarding.

APPENDICES

**1. Tools for data collection – Interview Questions for Users,
Carers and Members of the Public**

FOR USER 1:1 INTERVIEW

Introduction

1. Do you feel OK to talk here? Are you comfortable?

.....

2. In which language would you prefer to speak?

.....

3. When did you come to England? How long ago? How old were you then?

.....

4. Where do you come from?

.....

5. What was that experience like for you?

Well-Being

1. Did you face any problems/difficulties?

- | | |
|---|---|
| <input type="checkbox"/> ...Migration..... | <input type="checkbox"/> ..Nofriends/social/leisure |
| <input type="checkbox"/> ..Language difficulty... | <input type="checkbox"/> ..Health problems |
| <input type="checkbox"/> ..Trauma | |
| <input type="checkbox"/> ..Poverty/Housing | |

2. How has that affected you?

.....

.....

.....

.....

.....

3. Where would you go with this sort of problem? Who would you turn to for help if you were distressed?

- | | | |
|---|-----------------------------------|--|
| <input type="checkbox"/> GP | <input type="checkbox"/> Hospital | <input type="checkbox"/> Family/others |
| <input type="checkbox"/> Place of worship | <input type="checkbox"/> Healer | <input type="checkbox"/> Alone/Nowhere |
| <input type="checkbox"/> Library | <input type="checkbox"/> Internet | <input type="checkbox"/> Other |

.....

.....

.....

4. What has helped you to cope.

.....

.....

.....

.....

.....

5. Are there any activities you do which help mental well-being?

Hobbies	Groups	Outings
Gardening	Temple	Picnics
Housework	Prayers/Satsang	Trips/travel
Meditation	Family events – eg. parties	Seeing family
Singing/Dance	Exercise	Shopping
Reading		Walks
Writing		
Yoga		

6. Do you go to daycare/daytime social club? Does it help your state of mind?

Company of others

Activities

Lunch

Transport

7. Any more options for elderly people? Suggestions?

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.....

Mental Illness

1. a) What do you think your community thinks about mental illness/problems? What do you think about this?

b) What is your understanding of memory loss?
Is this process of getting older?

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.....
.....
.....

2. What are your views on this?

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.....
.....
.....

3. Which of these do you think might be mental health problems for older people?

	Memory loss
	Emotional distress
	Grieving
	Sadness/Depression
	Anxiety
	Madness
	Disturbed behaviour
	Hallucinations
	Confusion
	Suicidal

4. What do you think causes it?

Karma	Magic	God	Life events	Old age	Punishment	Medication side-effects

5. What can be done to help?

Indian medication, prayers/religion, mantras,
spirituality, rituals, exercise, yoga, diet, fasting, family support, music, arts?

	In general	What has helped you
Western medication/pills		
Ayurvedic/Indian med.		
Prayers/Religion		
Rituals/Mantra		
Exercise/Yoga		
Fasting/Diet		
Family Support		
Music/Arts		
Outings		

6. A) What has been useful for you?

.....

B) What help would you like?

.....

FOR CARER 1:1 INTERVIEW OR FOCUS GROUP

Introduction

1. Do you feel OK to talk here? Are you comfortable?

.....

2. In which language would you prefer to speak?

.....

3. When did you come to England? How long ago? How old were you then?

.....

4. Where do you come from?

.....

Well-Being

1. How long have you been caring? Do you face any problems and difficulties?

<input type="checkbox"/>	...Social exclusion	<input type="checkbox"/>	No
<input type="checkbox"/>	Friends/social/leisure		
<input type="checkbox"/> Trauma/health problems	<input type="checkbox"/>	
<input type="checkbox"/> Family Problems.....		Lack of Inf and Service
<input type="checkbox"/> Translation and		
	Interpreting		
		

2. How has the above affected you and your family?

.....
.....
.....
.....

3. Where would you go if you have a problem? Who would you turn to for help if you were distressed?

- | | | |
|---|-----------------------------------|--|
| <input type="checkbox"/> GP | <input type="checkbox"/> Hospital | <input type="checkbox"/> Family/others |
| <input type="checkbox"/> Place of worship | <input type="checkbox"/> Healer | <input type="checkbox"/> Alone/Nowhere |
| <input type="checkbox"/> Library | <input type="checkbox"/> Internet | <input type="checkbox"/> Carer Groups |

.....

4. What has helped you to cope.

.....

5. Which of the activities listed below you currently participate or would like to participate for your well-being?

Hobbies	Groups	Outings
Gardening	Temple	Picnics
Housework	Prayers/Satsang	Trips/travel
Meditation	Family events – eg. parties	Seeing family
Singing/Dance	Exercise	Shopping
Reading	Carer Groups	Walks
Writing	Breaks	
Yoga		

6. Do you have suggestions for well being for carers like yourself?

.....

Mental Illness

1. a) What do you think your community thinks about mental illness/problems? What are your views on this?
b) What is your understanding of memory loss?
Is this process of getting older?

.....
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.....
.....

2. What are your views on a caring role? Do you accept that it is your responsibility?
Does your family support you?

.....
.....
.....
.....
.....

5. What is your understanding of mental health illness? Which of the symptoms listed below contributes to the illness?

	Memory loss
	Emotional distress
	Grieving
	Sadness/Depression
	Anxiety
	Madness
	Disturbed behaviour
	Hallucinations
	Confusion
	Suicidal

6. What do you think causes it?

Karma	Magic	God	Life events	Old age	Punishment	Medication side-effects

5. What can be done to help people with mental illness?

	In general	What has helped you
Western medication/pills		
Ayurvedic/Indian med.		
Prayers/Religion		
Rituals/Mantra		
Exercise/Yoga		
Fasting/Diet		
Family Support		
Music/Arts		
Outings		

6. What has been useful for you?

.....

7. What help and support would you like?

.....

Introduction

1. Can we have a short round of introductions - When did you come to UK? Where do you come from? How old were you then?

- Respondent 1.....
- Respondent 2.....
- Respondent 3.....
- Respondent 4.....
- Respondent 5.....

Mental Illness

1. What do you understand by mental illness? What are your views on this?

Respondent
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.....
.....

Respondent
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Respondent
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Respondent
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2. What do you think your family and community thinks about mental illness/problems? Are they accepting them?

Respondent 1.....
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.....

Respondent 2.....
.....
.....

Respondent 3.....
.....
.....

Respondent 4.....
.....
.....

Respondent 5.....
.....
.....

3. What is your understanding of memory loss?
Is this process of getting older?

...Respondent
1.....
.....R
espondent

2.....
.....

Respondent
3.....
.....

Respondent
4.....
.....

Respondent
5.....
.....

4. Which of these do you think might be mental health problems to your understanding?

	Memory loss
	Emotional distress
	Grieving
	Sadness/Depression
	Anxiety
	Madness
	Disturbed behaviour
	Hallucinations
	Confusion
	Suicidal
	Other

5. What do you think causes it?

Karma	Magic	God	Life events	Old age	Punishment	Medication side-effects
1						
2						
3						
4						
5						

Well-being

1. Which of these activities do you think would help people with mental health issues?

Hobbies/Gardening etc	Groups	Outings/Trips/Travel
Interpretation/Translation	Temple	Picnics
Housework	Western Medication	Counselling
Meditation/Prayers	Family events – eg. parties	Seeing family
Singing/Dance	Ayurvedic/Indian med	Shopping
Reading	Talking to People	Walks
Writing	Watching TV/Radio	Day Centre
Yoga/Exercise	Arts & Craft	Community events

2. Do you and your community accept and encourage people with mental health issues and their carers into your community? And if so, how do you meet their needs.

Respondent 1.....

Respondent 2.....

Respondent 3.....

Respondent 4.....

Respondent 5.....

3. Which of the following activities do you or your community encourage them to participate?

	No. of Respondents
Satsangs	
Community events	
Prayers/Religion	
Rituals/Mantra	
Exercise/Yoga	
Talking to them	
Family Support	
Music/Dance	
Outings	
Arts & Craft	
Transport	
Learning Skills	

4. Any suggestions or comments?

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2. Information Sheet & Consent form



MIND IN HARROW GUJARATI ASIAN ELDERS RESEARCH PROJECT

INFORMATION SHEET

For people who have agreed to participate individually in the research

What is the research about?

Mind in Harrow has been awarded funding to manage an exciting research project to find out the attitudes towards mental health of Harrow Gujarati-speaking elders and those who care for them. This will then help to ensure more responsive services, tailored to the needs of older members of the community.

The project is funded by the National Institute of Mental Health England (NIMHE) and supported by the University of Central Lancashire's Centre for Ethnicity and Health.

How you can help us

Thank you for agreeing to an interview with us. We value your views. Your contribution will be greatly appreciated and has the potential to benefit members of your community.

How long will it take?

One of us will speak with you for about an hour, asking some questions to gain a better understanding of your community's attitudes, ideas and concerns around mental health.

Where will this take place?

We will meet you in the Mind in Harrow office, or visit you at home if you are unable to travel.

Will I be reimbursed?

We will pay you £20.00 for attending.

Will it be confidential?

Everything you tell us will be confidential and your details and any information will be completely anonymous. All interviews will be stored in a locked cabinet in the Mind in Harrow office. Once the final report is written, the interview sheets will be destroyed.

What if I change my mind about this?

Your participation is completely voluntary. You do not have to answer any questions which you find uncomfortable and you can stop the interview at any time, should you wish.

Damyanti Parmar Arvind Joshi
Gujarati Asian Elders Researchers

August 2007

-----Please tear off-----

CONSENT FORM

Mind in Harrow has a strict Data Protection Policy and undertakes to keep all information anonymous and strictly confidential.

Iam willing to participate in this research and I understand that my details and any information that I give will be completely anonymous.
Tick

I also understand that my participation is voluntary and that I can choose to not answer a question and I can stop the interview at any time.
Tick



3. Leaflets

GUJARATI ASIAN ELDERS RESEARCH PROJECT

MIND IN HARROW has been awarded funding to carry out an exciting research project. This project is funded by the National Institute of Mental Health in England (NIMHE) and supported by the University of Central Lancashire's (UCLAN) Centre for Ethnicity and Health. The purpose of the Gujarati Elders Research Project is to investigate the attitudes towards mental health problems of Gujarati speaking Asian elders resident in Harrow, and those who care for them, with a view to offering a more responsive service which is tailored to the needs of the community. We hope this project will help us to learn more about the ideas of the Gujarati community in Harrow relating to mental health problems in older people.

CAN YOU PLEASE HELP US?

We would like to get in touch with you if you are from the Gujarati-speaking community resident in Harrow, over 60 years old and suffering from mental problems; including those having a major role of caring for such older people at home.

We will be interviewing a number of people between September and November 2007 to gather views about the Gujarati community's attitudes, ideas and concerns relating to mental health to try and improve the understanding of local health care workers. The themes we intend to explore include:

- Understanding stigma
- Understanding mental health issues
- Appropriate treatments/alternative treatments
- Religious/Belief systems
- Language barriers

Some people will be interviewed individually, some in groups. Our researchers are bilingual in Gujarati and English. All participants will receive a thank you payment and we hope to contact people from a wide cross-section of the community.

INTERESTED?

Please contact:

Phone: Arvind Joshi or Damyanti Parmar
0208 5157858 or 0208 5157852 (Tues. & Fri 9.30-1 pm)
Messages can be left in English or Gujarati at other times.

Email: a.joshi@mindinharrow.org.uk or d.parmar@mindinharrow.org.uk

Post: Mind in Harrow, 8 Havelock Place, Harrow, Middlesex HA1 1LJ

YOUR CONTRIBUTION IS GREATLY APPRECIATED AND HAS THE POTENTIAL TO GIVE BENEFIT TO MEMBERS OF YOUR OWN COMMUNITY.



ગુજરાતી એશિયન એલ્ડર્સ રિસર્ચ પ્રોજેક્ટ (પરિયોજના)

માઈન્ડ ઈન હેરોને કોઈ એક ઉત્સાહજનક સંશોધનનો પ્રોજેક્ટ (પરિયોજના) કરવા નિધિ-ભંડોળ આપવામાં આવેલ છે. આ પ્રોજેક્ટનું નિધિયન ઈંગ્લેન્ડમાં નેશનલ ઈન્સ્ટિટ્યૂટ ઓફ મેન્ટલ હેલ્થ (NIMHE) કરે છે અને તેને યુનિવર્સિટી ઓફ સેન્ટ્રલ લેંકેશાયરના (Lancashires) (UCLAN) સેન્ટર ફોર એથનિસિટી એન્ડ હેલ્થ સમર્થન આપી રહ્યા છે. ગુજરાતી એલ્ડર્સ રિસર્ચ પ્રોજેક્ટનો આશય હેરોમાં ગુજરાતી ભાષા બોલનારા એશિયન વયોવૃદ્ધ રહેવાસીઓ અને જેઓ તેઓની સંભાળ રાખતા હોય તેઓની માનસિક આરોગ્યની સમસ્યાઓ પ્રત્યે વલણ કે વૃત્તિની તપાસ કરવાનો છે જેથી કરીને તેઓને વધારે પ્રતિભાવશીલ સેવા ઓફર કરી શકાય કે જે કમ્યુનિટી કે સમાજની જરૂરિયાતો પ્રમાણે સુસંગત હોય. અમે એવી આશા રાખીએ છીએ કે આ પ્રોજેક્ટ, વયોવૃદ્ધોની માનસિક આરોગ્યની સમસ્યાની બાબતમાં અમને હેરોની ગુજરાતી કમ્યુનિટિના વિચારો વિષે વધારે માહિતી- જ્ઞાન મેળવવામાં મદદરૂપ બનશે.

શું તમે અમને કૃપા કરી મદદરૂપ બની શકશો ?

જો તમે હેરોમાં રહેનાર ગુજરાતી ભાષા બોલનાર કમ્યુનિટિના, 60 વર્ષની વયની ઉપરના અને માનસિક આરોગ્યની સમસ્યાથી પીડાતા હો તો અમને તમારો સંપર્ક કરવાની ઈચ્છા છે; અને તેમાં જે લોકો ઘરમાં આવા વયોવૃદ્ધોની સંભાળ રાખવા માટે મહત્વની ભૂમિકા ભજવતા હોય તેઓનો આમાં સમાવેશ થાય છે.

અમે સપ્ટેમ્બર અને નવેમ્બર 2007 વચ્ચે સંખ્યાબંધ લોકોના ઈન્ટરવ્યૂ લઈ માનસિક આરોગ્યની બાબતમાં ગુજરાતી કમ્યુનિટિના વલણ, વિચારો અને ફિકર- ચિંતાઓ વિષે તેઓના દ્રષ્ટિબિંદુ મેળવી અને લોકલ હેલ્થ કેઅર વર્કર્સની (સ્થાનિક આરોગ્યની સંભાળ રાખનાર કાર્યકરોની) સમજમાં સુધારો કરવાનો પ્રયત્ન કરીશું. તપાસ કરવાના અમારા હેતુ - ઉદ્દેશના વિષયોમાં સમાવેશ થશે:

- કલંક કે લાંછનની (સ્ટિગમા) સમજ
- માનસિક આરોગ્યના પ્રશ્નો કે મુદ્દાઓને સમજવા વિષે
- યોગ્ય સારવાર / વૈકલ્પિક સારવાર કે ઉપચાર
- ધાર્મિક / માન્યતાવાળી પદ્ધતિઓ
- ભાષાના અવરોધો

થોડાક લોકોનો ઈન્ટરવ્યૂ વ્યક્તિગતરીતે કરવામાં આવશે, ત્યારે અમુકનો ગ્રૂપ કે સમૂહમાં. અમારા સંશોધનકો ગુજરાતી અને ઈંગ્લિશમાં દ્વિભાષી હશે. ભાગ લેનારા બધાજ લોકોનો આભાર માનવા માટે નાણાની રકમ ચૂકવવામાં આવશે અને અમે કમ્યુનિટિના વિશાળ સર્વગ્રાહી પ્રતિનિધિત્વવાળા લોકોનો સંપર્ક કરવાની આશા રાખીએ છીએ.

શું રસ છે ?

કૃપા કરી સંપર્ક કરો:

ફોન: અરવિંદ જોષી (Arvind Joshi) અથવા દમયંતી પરમાર (Damyanti Parmar)
0208 5157858 or 0208 5157852 (મંગળ અને શુક્રવાર સવારના 9.30 થી બપોરના 1)
બીજા સમયે ઈંગ્લિશ અથવા ગુજરાતીમાં સંદેશાઓ છોડી શકાય.

ઈમેઈલ: a.joshi@mindinharrow.org.uk or d.parmar@mindinharrow.org.uk

પોસ્ટ: Mind in Harrow, 8 Havelock Place, Harrow, Middlesex HA1 1LJ

તમારા ફાળા - હિસ્સાની ખૂબજ કદર કરવામાં આવે છે અને તમારી પોતાની કમ્યુનિટિના સભ્યોને તેથી લાભ કે ફાયદો થવાની સંભવિતા રહે છે.



For better
mental health

Mind in Harrow
8 Havelock Place
Harrow
Middlesex HA1 1LJ

www.mindinharrow.org.uk

Registered charity number 1067480