

The Asian Women's Group Empowering Women



The Asian Women's well-being project
Report prepared
By Aziza Shafique
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### Aziza Shafique

# **Executive Summary**

# Background: Asian women's Health

People from Asian communities form the largest minority ethnic group in Oxfordshire and within Oxford city in particular. South Asians (Indian, Bangladeshi, Pakistani or Sri Lankan origin) can be up to six times more likely to have diabetes than the general population. Pakistani women are especially at risk. The risk of dying early from coronary heart disease is twice as high among South Asians as compared with the general population. There are many cultural dimensions to improving health and wellbeing, as there are to understanding illness, which is particular to the Asian community. The socio-economic pressures of a low income, home based, sedentary lifestyle are associated with poor diet, being over-weight and higher incidence illnesses such as diabetes and mental health issues - above the average for the general population. Cultural issues, stigmas and taboos also have an influence on how mental health issues are viewed and addressed at an individual level.

Women are the mainstay of the family – with men working long hours to support their families, often leading to a somewhat limited and isolated social interaction for women. Strong religious beliefs, duty and extended family relationships are a central part of the Asian culture and have an influence on attitudes towards and perceptions of health services.

#### The research

Against this background of an increasing Asian population, specific health risks and health needs, some cultural barriers surrounding access to GP services, domiciliary care, and mental health, the Asian Women's Group and Healthwatch Oxfordshire decided that a research project engaging with Asian women to probe their experiences and attitudes around these three areas was a priority.

A semi-structured qualitative-quantitative methodology was chosen, with a degree of deliberate informality. Participants took part either in the focus groups, face to face interviews or a "What Matters to You" questionnaire based interviews and discussions, as well as more informal forms of engagement at leisure centre talks and on a coach trip. Data was collected in four local communities by volunteer facilitators from local families in Rose Hill, Cowley, Woodfarm and Headington areas of Oxford, where there are large populations of Pakistani, Afghani, Bangladeshi and Arabic families, and also in Ruscot and Woodgreen, Banbury. Participants tended to be of working age, working part time and often had caring responsibilities as well. 28 women took part in focus groups, over 130 women took part in informal discussions and interviews on a targeted coach trip and an international women's day event. 101 women responded to a survey, in many cases with support from an interpreter. 143 women took part in the project overall.

Gross household income was mainly under £20,000; with eligibility for benefits - and most participants claiming a range of benefits, living in owned or private rented housing often with several children, parents – and/or parents in law.

# **Key Findings and Recommendations**

# **General Practitioners**

One significant finding of the research was that despite some dissatisfaction surrounding GP access, most Asian Women visit their GP at least monthly. GP services are by far the most frequently used health service by the majority of Asian Women.

Many women reported cultural barriers to accessing services such as feeling embarrassed talking to someone they don't know, or their husband not liking them seeing a male doctor or nurse and having to relying on a family member such as daughter or daughter-in-law mainly to act as interpreters or carers. Sometimes their children or husbands fulfilled these roles. Unfriendly receptionists at GPs surgeries and language difficulties were other barriers to access that were reported. Participants said they did not know how to complain or were not confident in doing so.

# **Access to Services (General Practice)**

Many found initial access to all health services was either only "acceptable" or "harder than expected". Barriers to using health services included lack of transport or support, language barriers and lack of adequate information. Many women choose to travel to services where they know they will be respected and there is a cultural understanding and/or their language is spoken. This creates transport and access issues. The extended families' needs were not always considered - and in some cases greater support for husband and close family members needs to be in place.

#### **Recommendation 1:**

1. The provision of culturally aware GP surgeries and drop-in appointments with GPs in accessible centres with a less formal structure (e.g. clinics in appropriate community settings or children's centres), and support to overcome the barriers Asian women face accessing GP services, such as women feeling embarrassed by consulting with a male doctor, or practices failing to recognise the need to have Halal medication.

### **Mental Health**

Although it is difficult to quantify from this study, many Asian families appear to suffer from mental health issues and there is a lack of support around seeking medical advice. Mental health is often seen as a taboo subject and kept hidden from extended family members and local communities. It is something "to be kept private". Race, language, culture and religion

play a big role in how mental health is perceived in some Asian communities. More support is needed to encourage women to seek medical advice.

# Recommendation 2 (mental health):

The need for educational work within the Asian community **to reduce stigma and promote understanding about mental health issues**. The call is for the provision of more community outreach to:

- support women from the Asian community who have had experience of mental health issues themselves, so that they in turn can support isolated women in their own homes and provide information and signposting to services;
- work with the wider community and facilitate support groups to eradicate cultural myths around mental illness.

# **Domiciliary Care**

Despite the increasing numbers of older people amongst the Asian population, most Asian families care for their family members themselves at home as much as possible. Daughters and daughters-in-law are the main carers for the elderly or disabled elders. The cultural expectations that an elderly family member would be cared for at home, as far as possible, poses many challenges for women carers — who usually have young families too. There are strong cultural and religious pressures to accept and taking on a caring role means the recipient of care becomes highly dependent on daughters, daughters-in-law, or wives. For this reason it appears that domiciliary care services are not as widely taken up as in the general population. However in situations where domiciliary care services are taken up, once carers and clients have built relationships and learnt to appreciate the different cultural and religious needs these domiciliary services are generally very well regarded, providing valuable support, respite and additional socialisation.

# **Recommendation 3:**

Better information and support to enable the take up of **help available for families caring for family members at home** (including direct payments and personal budgets). There is a need for **more research to identify the needs of the disabled and elderly** and training to put culturally appropriate care packages in place.

# **Background**

The Asian women's group is a constituted community group with 18 members on the steering group. This was developed in 2009 as a result of a needs analysis undertaken by the Rose Hill and Littlemore Children's Centre in 2006, which highlighted that Asian women in Oxford face many challenges when accessing mainstream services, and are often "hard to reach" because of social isolation, racism in communities, organisations and institutions. In addition they have the further challenges of language, cultural, religious and social barriers. The current, harsh reality is that the Asian community is often associated with poverty, deprivation, overcrowded housing, poor health and early death.

'South Asians' (a description also used to describe anyone of Indian, Bangladeshi, Pakistani or Sri Lankan origin) each have their own unique culture and background, however they all share some common health issues.

- **1.** People from South Asian communities can be up **to six times** more likely to have diabetes than the general population. Pakistani women are especially at risk.
- **2.** The risk of dying early from coronary heart disease is **twice as high** among South Asian groups compared with the general population.
- **3.** Experts aren't sure why this is the case, but it may be linked to diet, lifestyle and different ways of storing fat in the body.

Source: <a href="http://www.nhs.uk/Livewell/SouthAsianhealth/Pages/Overview.aspx">http://www.nhs.uk/Livewell/SouthAsianhealth/Pages/Overview.aspx</a>

Women from South Asian countries suffer more health issues as a result of many different life factors including poverty, educational attainment, employment, disability, housing conditions and psychosocial factors.

Large-scale surveys like the Health Survey for England in "Disease in Different Ethnic Groups" show that black and minority ethnic groups on the whole are more likely to report ill health, and that ill health among black and minority ethnic people starts at a younger age than in the White British population.

Source: http://www.patient.co.uk/doctor/Diseases-and-Different-Ethnic-Groups

According to Diabetes UK - Children of South Asian origin in the UK are more likely to have type 2 diabetes than their Caucasian peers. Weight gain caused by eating traditional foods high in sugar and fat, alongside Western "fast foods", is thought to be a contributing factor.

Oxford is increasingly an ethnically diverse city as shown in the changes between the 2001 and 2011 census.

People from Asian communities form the largest minority ethnic group in the county.
 Most come from Indian or Pakistani backgrounds (2.45%)

- The largest Non-White ethnic groups represented in Oxford are Pakistani, Indian, Black African, 'other Asian' and Chinese ethnic groups.
- 4.8% of the population are from Asian backgrounds, twice the 2001 figure of 2.4%.
- The number of people from all ethnic groups increased, with the exception of people in the White British and White Irish ethnic groups.
- All the county's Black or Minority Ethnic communities have grown and now account for 9.2% of the population, just under double the 2001 figure of 4.9%
- 22% of residents were from a black or minority ethnic group in 2011, compared to 13% in England.
- An additional 14% of residents are from a White but non-British ethnic background.
   There has been a growth in this section of the community, who now account for 6.3% of the population. Much of this increase is explained by the movement of people from the countries which joined the EU in 2004 and 2007
- The child population is considerably more ethnically diverse than the older population, which is one reason why the population is expected to become even more ethnically diverse in the future.

**Source:** Oxford City Council Insight Ethnicity data: http://www.oxford.gov.uk/PageRender/decC/Ethnicity\_occw.htm

It is well known that Pakistani women are at greater risk of early death. Also, the death rate from coronary heart disease is higher among South Asian men and women who were born outside the UK than it is among the general population. New healthy weight advice was issued in July 2013 to South Asian adults to try to address some of the weight related lifestyle issues by the National Institute for Health and Care Excellence (NICE).

http://www.nhs.uk/Livewell/SouthAsianhealth/Pages/Overview.aspx

# The reason for the research project

Against this background of an increasing Asian population in Oxford, particular community health needs, reported cultural issues surrounding access to GP services and Domiciliary Care and Mental Health, the Asian Women's Group and Healthwatch Oxfordshire decided a research project would be helpful to probe what is underlying these issues. The Asian Women's Group and the Oxfordshire Community and Voluntary Action (OCVA) 2011/2012 study on Stigma surrounding Mental Health issues within the Asian community had increased awareness amongst Asian women of mental health, and provided valuable insights into, and demonstrated the value of discussing hitherto taboo and cultural challenges.

The Asian Women's Group, in consultation with Healthwatch Oxfordshire, decided to raise awareness of health and lifestyle issues among Asian women and other ethnic minority

women, (Afghani, Arabic, Pakistani, Bangladeshi and Somali) in parallel to carrying out the Asian research project.

# The aims of the Asian Women's Group (AWG);

- 1. To involve and include isolated women from South Asian communities to come together and learn/share their skills and values in order to build a network.
- 2. To promote the health and well-being of Asian women
- 3. To empower Asian women to support each other in challenging some of the inequalities in society.

# AWG's objectives;

- To work in partnership with government and other organisations in identifying gaps and barriers and work with them to improve services to make them accessible to South Asian families.
- To run community led weekly support groups in Oxford to enable Asian/ethnic minority women to develop self-esteem and confidence
- To support and signpost Asian women to access local health services, Children's Centres, parenting groups, English as a second language classes and job centres.

Most families use health facilities on a regular basis. However, we were aware that a combination of personal, socio-economic, cultural, political and environmental barriers may discourage families from South Asian groups from accessing some mainstream health services. In addition we were aware that racial, cultural and language barriers may also contribute to the lack of understanding of the needs of Asian communities and the services they use.

The Asian Women's Group was funded by Healthwatch Oxfordshire, a new independent champion for everyone who uses health and social care services in Oxfordshire, to gather views about three priority services:

- 1. Access to GP services
- 2. Mental Health Services
- 3. Domiciliary Care (Home care services)

The information will be used to help improve services for Asian Women and to enable Healthwatch to understand what really matters in improving health services. The findings

and recommendations will be used to feed in to the current and future work of the Health and Wellbeing Board to improve the health and wellbeing of Asian Families in Oxfordshire.

# The aims of the research project:

- 1. To seek and gather Asian Women's experiences, attitudes and views of the above three identified areas and feed these in to the Oxfordshire Health and Wellbeing Board which informs policy decisions, strategy development and programme delivery with the ultimate aim of improving health progressively and sustainably in Oxfordshire at excellent value to public.
- 2. To make sure data is robust and relevant and represents the public's views in an unbiased and objective way.
- 3. To devise and deliver an effective needs analysis which can influence commissioners to plan appropriately for the Asian Community in Oxfordshire.

This targeted work took place over a three month period, between January 2014 and March 2014.

# Methodology

Data was collected in four local communities by volunteer facilitators from local families in the Rose Hill, Cowley, Woodfarm and Headington areas of Oxford, where there are large populations of Pakistani, Afghani, Bangladeshi and Arabic families.

The volunteers spoke nine languages between them such as, Urdu, Punjabi, Hindi Bangladeshi, Sylheti, Pashto, Gujarati, Farsi and English. The facilitators and all the women interviewed were all local parents living in Oxford.

Home based interviews were also carried out in two different areas in the Wood Green and Ruscote areas of Banbury with Pakistani and with Afghani women.

The methods used to capture a cross section of the Asian Women's Community views included both qualitative and quantitative tools:

- Focus groups (interactive group work)
- Interviews at home (one to one interviews)
- Questionnaires (one to one)
- **Discussions in Leisure Centres** (some group discussions and some one to one conversations)
- Coach trip to Birmingham (group discussions)
- International Women's day (general informal discussions)

# **Focus Groups**

These took place over six weekly sessions, with about 2 hours for each session in two areas of Oxford City: Rose Hill and Cowley. The focus groups were run by two facilitators interpreting in four different languages (Urdu, Punjabi, Hindi and Pashto) and translating in two languages (Urdu and English) (see appendix 1 and 2).

These were interactive sessions with the facilitators prompting; probing, summarising and identifying collective themes on each topic. During the discussion 14 women took part in each focus group. Out of the 28 women who took part in the two groups all women spoke English as their second language, 12 could speak reasonable English and 16 spoke very little or were beginner learners of English.

# The focus groups consisted of:

- Mothers of young children or pregnant women
- Carers of elderly relatives
- Users of services such as hospitals and local GPs
- Women who suffer from depression or anxiety
- Women from families with low incomes

# Interviews in Women's Homes in Oxford and Banbury

In addition to the focus groups we carried out five interviews at home. These were carried out by two facilitators who had undertaken one to one interviews in the community. Interviews lasted between 30 minutes to one hour each. Two women were interviewed in depth about access to GP practices, two who had experienced mental health issues and one who used domiciliary care. A simple open questions approach was used:

- 1. How do you find access to your GP?
- 2. What are your thoughts around mental health services in Oxfordshire and do you use any Mental Health services?
- 3. Do you use carers to care for your relative (at home). If so how do you find the service?

# Birmingham coach trip

The primary aim of the Birmingham coach trip was to get feedback from women using domiciliary care. Trips are always a good opportunity to share ideas, information and advice and to offer support to women and for them to offer support to each other. The Birmingham trip proved popular and was enjoyed by 42 women from different backgrounds. The trip was aimed at women who find it hard to get out of their homes and take a break due from caring for family members. Four workers assisted this trip gathering views during group and individual discussions.

# **International Women's day**

This was a final celebration of the project. More than 90 women from diverse backgrounds took part. Conversations took place around Mental Health and Domiciliary Care.

# **Finding and Analysis**

#### Questionnaires

We carried out questionnaire based discussions about women's experiences and their thoughts and feelings about the health services they use. Discussions took place in three Leisure Centres, Children Centres and in service users' homes. Most respondents were of working age: 25-40 or 40-60 years (see pie chart). We had hoped 130 questionnaires would be completed; however 29 questionnaires were given out and not returned. As a result of this we decided to adapt our approach and sit with women and help them individually as necessary to complete the questionnaires. In this way we were able to achieve 101 completed questionnaires to gather the Asian women's perspectives on all three priority areas – GP access, Mental Health and Domiciliary Care. This is approximately 1% of the total population of Asian women in Oxford (2011 census).

# **Analytical results**

# a) Information about the respondents

Most respondents were of working age: 25-40 or 40-60 years.

Table 1

Age Group	Number of respondents
18-25	19
25-40	49
40-60	25
over 60	7
Not reported	1
Total	101

The range of occupations reported ranged from full or part time employment, to full time housewife, to full time carer. Many (nearly one-quarter) have a combination of part time work, housework, and caring responsibilities.

Table 2

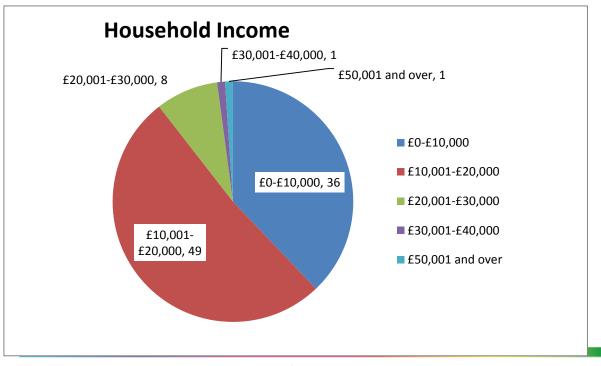
Occupation	Number of respondents
Full time	10
Part time	38
Housewife	34
Care for children or elderly	10
Other	9
Combination of work and care	23
responsibilities	

Nearly half of respondents reported their gross household income as being £10,000 to £20,000 per year and 36 reported household incomes under £10,000. Only 2 respondents reported a household income of over £30,000 per year.

Table 3

Household income	Number of respondents
£0-£10,000	36
£10,001-£20,000	49
£20,001-£30,000	8
£30,001-£40,000	1
£50,001 and over	1
Not reported	6





We undertook the questionnaire interviews in six different languages: Urdu, Punjabi, Hindi, Pashto, Bangladeshi and English. This was carried out by 4 key members in the community who were fluent in the above languages.

The data collected and the identities of the respondents were kept strictly confidential. All of the analysis is reported in aggregate form rather than as individual responses. Most (84 out of 101) respondents reported claiming benefits of some kind. 60 claim child benefit. Very few claim job seekers allowance. Over half claim a combination of benefits.

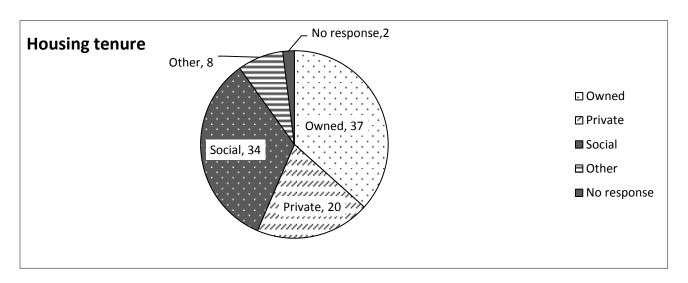
Table 4

Benefit	Number of respondents
Working tax credit	47
Child benefit	60
Childcare and tax credits	11
Jobseeker's Allowance (JSA)	3
Employment and Support Allowance (ESA)	2
Pension Credit	9
Income Support	4
Disability Living Allowance (DLA)	14
Carer's Allowance	4
Combination	53

Over half of respondents (57 out of 101) live in owned or private rented housing. One third (34 out of 101) live in social housing, and 8 reported living in "other "accommodation such as with another family member.

Table 5

Housing tenure	Number	of
	respondents	
Owned	37	
Private rented	20	
Social	34	
Other	8	
No response	2	



In summary, the respondents tended to be of working age, working part time, often with caring responsibilities as well, with a household gross income under £20,000, eligible for and claiming a range of benefits, and living in owned or private rented housing.

#### **Access to GP Services**

Through the discussions and flip chart exercises four key themes emerged, centred on:

- Race
- Language
- Culture
- Religion

The women in our groups discussed their lifestyle and social and financial issues. Most families were on a low income and the women were bringing up children on their own due to husbands working long hours and receiving low wages – all this contributed to create more stress related illness and poorer health. Some women are living in poverty, in social housing and poor conditions, often with extended families in overcrowded houses. One Asian woman explained "I've had high blood pressure and diabetes since I was 23 years old and my GP said it is due to your race and culture...I often visit my GP more than once a week and find accessing my GP practice good"

# "I like my GP Practice I find it friendly and easy to access." (Appendix 3)

The discussions in both groups highlighted living standards and lack of education, contributing to poor health in women and children. Ten out of fourteen women in the group said two or more of their family members suffer from asthma, diabetes and at least one other health issue - which means more appointments and visits to GP surgeries and

hospitals. The women talked about some racist attitudes towards women by some receptionists, their first point of contact and said...

"My receptionist is so rude, if we cannot get pass the receptionist what hope is there"

Other women said

"I do not know where to complain" (See appendix 3)

# a) Use of health services

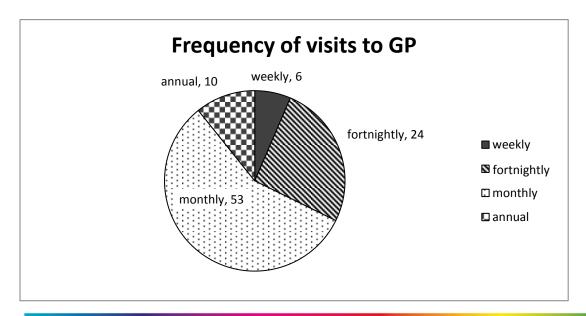
Of the 101 respondents 51 reported that they use mental health services, almost all (96) see their General Practitioner (GP), and 23 use Home Care. Many of the respondents (59) use a range of services, for example of the 96 who see their GP, 50 also reported using Mental Health services and 21 also use Home Care services.

Table 4.6

Service used	Number of respondents
Mental Health	51
GP	96
Home Care	23
Other (specific hospital services)	2
A combination of services (2, 3 or 4 services)	59

Most respondents report that they see their General Practitioner (GP) at least once a month.

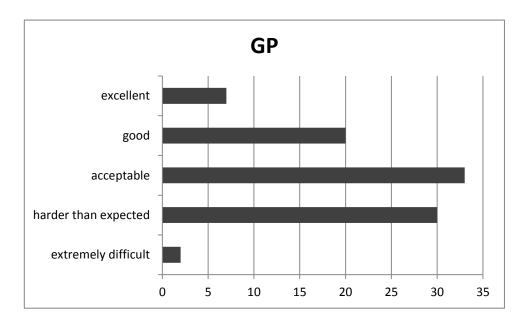
Chart 3



# b) Ease of access to services

Many respondents reported that they found initial access to General Practitioner (GP) services harder than expected (30) or acceptable (33) out of the 92 responses received on this question. 20 reported that they found initial access to be good, 7 found it to be excellent and 2 found it to be extremely difficult.

Chart 4



There were too few respondents to report on ease of access to initial access Mental Health services (43 responses) and Home Care (32 responses). However, in aggregate, the responses on access across all 3 service areas showed that most respondents found initial access to be either acceptable or harder than expected

# **Barriers to Accessing GP Services**

Geographical areas created physical barriers to accessing GP services, as most women travelled further out of their area to visit their GP surgeries. Reasons cited for doing this were:

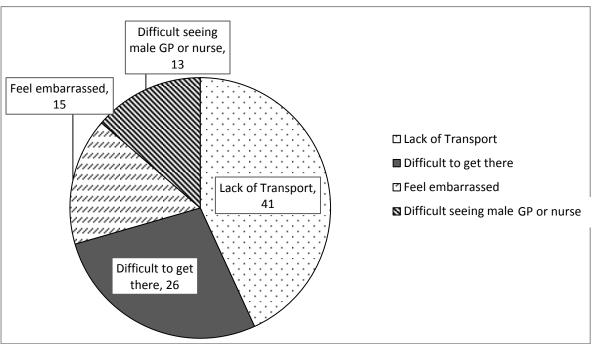
- A good relationship with their GP
- Confidence and trust in their GP
- GP coming from a similar culture
- GP speaking the same language
- GP recommended by other family member
- Feeling loyal to their GP, if they have been with them for a long time

This in itself creates additional challenges to get to the GP practices such as:

- Lack of transport to and from their homes to doctor's surgery because most of the women do not drive
- Having to change buses to get to their GP surgeries
- Bus fares and taxis costing too much
- Not feeling like going to the surgery on their own or family barriers with regards to going out alone
- Experiences of racism and Islamophobic attitudes on the bus on the way to the doctor's surgery.

62 of the 101 respondents reported having difficulties accessing services. Many of their difficulties related to problems getting to the service, due to lack of transport (41 responses), finding it difficult to get there without support (26), feeling embarrassed talking to someone that they do not know (15), or their husband not liking them seeing a male doctor or nurse (13 responses).

Chart 5



#### **Language Barriers**

It was clear from the discussions that in most cases language was a significant barrier accessing GP surgeries because all the leaflets, flyers, posters on the wall and the appointment cards were written in English. Some women in the group could read basic English, but others could not read English. Very few women wrote and read Urdu as their first language. Some women said they use family members or husbands to interpret for them. The women felt they were not treated properly due to language barriers.

"They don't take me seriously because of language barriers" (see appendix 3)

"I can't speak English and the receptionist does not help, very rude" (See appendix 3)

Most women felt that the GP surgeries do not make an effort to get interpreters from outside and expect patients to bring a family member to interpret for them. This presents the following problems:

- Women's confidentiality is compromised
- Interpreting for a family member may not accurately reflect the women's concerns or feelings
- Women may feel embarrassed to have to take children with them to interpret for personal issues
- Depending and relying on husband or other relatives to be available at the time of medical need (this often means having to wait longer for an appointment)
- It costs, time and money

Some women felt they had no choice but to take whoever was available to appointments as one woman explained,

"I had to take my 12 year old son to talk about having a hysterectomy. It was so embarrassing for both of us."

One woman explained,

"I live in an extended family with my two sisters in law, and my father and mother in law. We cannot afford to live separately as my husband is the only earner in the house. My mother in law has heart disease. When I phone up on her behalf to get an appointment in an emergency it is hard accessing my GP. I only contact a doctor when she is in pain or needs help and when my doctor's surgery do not answer the phone or get back to me, I get really frustrated. I often end up taking her to Accident and Emergency"

Another woman said,

"Communicating with my GP is a real issue as I do not understand his language and culture and he does not understand mine, I have to rely on my husband to interpret for me."

Cultural issues can affect many aspects of health and was highlighted in focus groups; there is a cultural difference between the majority white culture and the ethnic minority cultures. Understanding different cultures can support access to health and social care organisations. For example in some South Asian communities families live as extended families with the mothers and fathers- in-law seen as head of the family and the ones who make decisions on all aspects of the family's life. The whole family may be involved in decision making such as signing consent forms for operations, for how and when treatment should be taken and booking appointments. The other big cultural difference is that in some South Asian countries the private health care is provided and in some rural areas in Pakistan, Bangladesh and India there is no appointments system and women just informally drop in and get treated. The women talked about a number of cultural barriers when accessing GP Practices:

- The cultural expectation of the medical care in general
- Different attitudes to sexual relationships and marriages
- Different attitudes to male doctors with women patients
- Different attitudes to social life of women
- Feeling embarrassed by talking to a male doctor

Some women find formal structures, such as booking appointments, waiting for a blood test or letter from the hospital, a challenge which can lead to frustration.

Religion plays a vital role in Asian families' lives and is a way of life. Islam encourages healthy lifestyles and behaviours play a vital role. There are many health benefits to be gained by adhering to Islamic morals and ethical and ritual practice. For example, the Quran prescribes breast feeding an infant for 30 months, promotes personal hygiene, emphasizes the significance of purity and hygiene for performance of daily prayer, prescribes avoidance of intoxicating drinks and smoking and offers guidance on parenting and human rights for everyone. The body has rights and seeking medical help is seen to fulfill the rights of your body. Illness and health have a spiritual dimension and illness can be seen as divine and a test from Allah that purifies the soul.

All the women in our focus groups were Muslim and were from diverse backgrounds and cultures. We discussed how religion may be a barrier to accessing health services and the women responded that it is not a big barrier as such - but there are important facts to be aware of, for example:

Muslims are prescribed to pray five times a day, with Friday being the special day
where most Muslims have to cleanse themselves to go to their mosque to pray. Any
appointments booked on Friday need to coincide with Friday prayer times.

- Muslims fast for one month for Ramadan every year, except for those who are ill, having blood transfusions, taking medicine or pregnant. Drinking any liquid during daylight is forbidden and with long summer days this can be for up to 18 hours, so access to GP practices need to be avoided during this month if at all possible and it is vital that this is considered when prescribing medication.
- Halal foods are foods that Muslims are allowed to eat or drink under Islamic Shari'ah. The criteria specify what foods are allowed, and how the food must be prepared. The foods addressed are mostly types of meat and animal tissue. The most common example of non-halal (or haram) food is pork. While pork is the only meat that cannot be eaten by Muslims at all (due to historically perceived, cultural and religious concerns around hygiene), foods other than pork can also be haram. The criteria for non-pork items include their source, the cause of the animal's death, and how it was processed.
- Most capsules tablets are made of gelatine, animal fat, which is considered haram for Muslims.
- Male circumcision is also a religious requirement for boys usually carried out in the first year of their life.

Understanding the religious, cultural and language needs of patients can improve the health and well-being of families and will support the family to access all services provided.

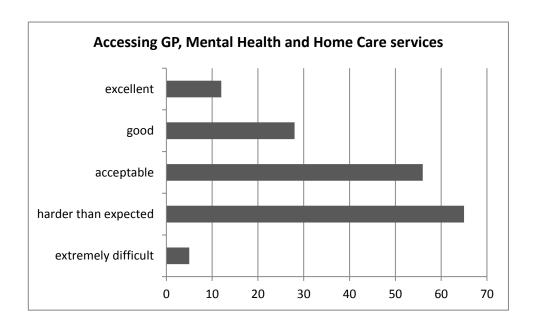
#### **Mental Health services**

Many Asian families suffer from mental health issues and lack the support needed to seek medical advice. Mental Health is a hidden issue and considered as something that is to be kept private. This is something that was strongly emphasised in the focus groups (see appendix 5).

Race, language, culture and religion play a big role in how mental health is perceived in some communities. Mental health is seen as a taboo subject, with many families trying to keep it hidden from extended family members and local communities.

The work carried out in the groups and for home interviews was carefully worded because of the sensitivity around how mental health is perceived by some Asian communities. The workers that led the group discussions and did the home interviews had previously suffered some form mental health issues themselves so they could empathise with them.

In reporting the types of mental health services that they use, only 1 respondent reported using Cognitive Behaviour Therapy, 1 reported using counselling/talking therapy, and 1 reported using some other type of service (not specified). Most respondents (69) reported using GP prescriptions (and many specified that this was for stress or depression).



The women talked about the barriers they face when suffering from depression and other forms of mental health. One woman said,

"I faced additional challenges on a daily basis and was made to feel guilty and incompetent when I had depression."

Some families are in denial of their own and maybe a family member's mental health issue. Family and community members may believe that depression, for example:

- Is something to be ashamed of and is embarrassing.
- Is not something you talk about
- Does not exist and is made up.
- Is a short term thing that will go away
- Is not something doctors can do anything about

Many mental health illnesses are seen as:

- a curse to the family
- black magic cast on the individual or family
- a spell cast on you by someone who wants to harm you
- punishment for past sins
- being a sinful person

A family member with mental health issues may often deny themselves the opportunity to go out and interact with the rest of the community and consequently they deprive themselves of benefits of the wider learning and development that comes from networking and engagement with the rest of the society.

This means that the person suffering with mental health issues is discriminated against by their own community and the wider society and therefore faces even more isolation. One Bangladeshi woman told her story of her suffering and the stigma she faced in her own culture and the majority culture. (See appendix 5 flip chart sheets of the group's views on mental health issues)

# Case study 1

"I am 36 years old Bangladeshi woman and I came to England fifteen years ago with my husband. I live in a 3 bedroom house owned by a housing association with my husband who is deaf and can't speak and my four children aged between 13 years and two years old. My husband has severe learning difficulties and is dependent on me to support him. Two of my children are also deaf but can speak enough so I can understand them. We have been on benefits all the years I have migrated to England."

..."I have learnt a few words of English but cannot communicate fluently in English and face many challenges on a daily basis to keep the family going."

... "Three years ago when I was pregnant with my last child I experienced severe depression and felt I could not cope with life any more. I often had headaches and could not get out of bed in the mornings and did not want to eat. I felt I was no use to this world and often thought of ending my life and as the days went by my feelings of taking my life became stronger and on a number of occasions my thirteen year old son stopped me from overdosing myself and he became my carer."

"I do not have any family in this country and my husband's family stigmatised me as mad and said you've got a spell on you and you should purify yourself and get on with it. I felt so lonely and hopeless."

"My husband did what he could to keep the house going, but at times would get frustrated with me saying you are putting it on. I was hoping his social worker would come and see the situation but my husband was ashamed of my actions and cancelled the appointment by my thirteen year old saying we are going away for a month."

"My doctors surgery is in a different area and the reason I chose that is because there were Bangladeshi speaking health advocates there so it made it easy for me

to explain stuff and get support but that service was finished due to cuts and I felt alone. Travelling to my doctors was a challenge because I did not drive and had to change several buses and I could not speak English."

"I rang to book an appointment with my GP and the receptionists could not understand that I needed an urgent appointment because of language barriers I got an appointment two weeks later. I was so desperate I didn't like what was going on with me - and the children did not attend school for weeks, as I had no energy to organise them and get them out of bed to go. My thirteen year old son had spoken to a Bangladeshi teaching assistant in school explaining why he had not attended school and the lack of support for me. She visited me at home and assisted me to the doctors and explained what had happened to the doctors. I was assessed straight away and was sent to psychiatric ward in hospital where I received treatment and care until I was able to come home. The children were offered support by a support worker. I received care after I came home for six months which supported me to take medication and take care of myself and my new-born baby girl. I am still getting a lot of stigma because of my depression from the Bangladeshi community, some people will say hello and do not have conversations with me because they say you have a mental issue meaning you are mad but I am strong and will carry on for the sake of my children, I have a strong faith and praying gives me strength."

This case study highlights many of the challenges of being an Asian woman with a mental health issue and the stigma and difficulties they face as a result. Furthermore a short term project carried out in 2011-2012 by the Asian Women's Group funded by Oxfordshire Community and Voluntary Action (OCVA) highlighted the prejudice and oppression experienced by women with depression and the stigma attached to Mental Health issues (see Appendix 7)

#### **Domiciliary Care**

The elderly population in the Asian community is rapidly increasing with most Asian families caring for their sick or disabled family members at home. The role of daughters and daughters-in-law is becoming increasingly important in the care of elderly or disabled elders. The cultural expectations that an elderly person would be cared for at home as far as possible pose many challenges for women who care for their elders. Most families do not access any services because they feel there is a lack of services appropriate to their culture and religion. This means the care becomes dependent on the daughter, daughter-in-law, or wife in most situations.

In some cases the support that's provided by health and social care services is taken up and much appreciated by the carers because it offers them and the client a break because it is contact with the outside world which increases wider social interaction.

On the trip to Birmingham we discussed domiciliary care in the Asian communities.

The women talked about how it feels to depend on someone for daily life and routine activities and the frustrations that comes with dependency. As one woman said,

"I used to live an independent life and after my accident I depend on other people for personal care. It is so sad."

They talked about the importance of understanding, caring and empathic carers to provide the care. One woman said,

# "It makes all the difference when they turn up with a smile"

Attitudes and behaviours of care providers was the main topic on the way to Birmingham. From these discussions we identified the following issues with regards to home carers:

- Lack of cultural understanding and religious events by carers
- Need for a clear understanding about the person they care for.
- Consistency in carers as the women stated that they have different carers in and out all the time. When relationships are building with one carer "they change the staff over".
- Language and cultural barrier needs to be taken in to account
- More time needs to be spent with the carers.

On the other hand carers were also praised for:

- Being friendly and smiley
- Providing good services
- Having a flexible approach
- Having a willingness to learn about different cultures
- Trying to communicate with pictures
- Being respectful to our religion

Overall the feelings were positive towards care providers as demonstrated in this case study (see appendix 6).

## Case study 2

"I am a 44 year old Pakistani woman, I suffer from a severe form of Arthritis and cannot perform day to day duties for myself - therefore I am dependent on family members to care for me.

I live with my daughter in law who took care of all my personal care such as helping me out of bed each morning to have a wash and get changed, making my

breakfast, lunch and dinner and doing my washing. I tried to keep active but my condition was getting worse and after a stroke... my care needs became more intense... I became bedbound. At first my daughter and daughter in law were reluctant to have outside care and were determined to care for me themselves as they felt it dishonourable and disrespectful to have outside care.

They took it in turns to share the care for four years but I could see them struggling to juggle with their own family's needs and my care needs and I was so relieved when my care manager came and talked to them about sending in carers from an agency that are employed by social services.

It took a lot of convincing and encouragement to agree to outside care so we started as a trial and thought let's see how it works out but after a while I got used to them and my daughter and daughter-in law were relieved as it allowed them to do more for their families."

"I look forward to my carers every morning; they are part of my family"

The woman acknowledged that most people do not access outside care and lack of information prevents people accessing services.

# **Strengths and Limitations of the Project**

# Strengths of the project

- The existing relationships with the women
- Delivered in local communities by local groups
- We reached 143 women in this project
- The project was delivered in five different languages including English
- Working with women in their own homes
- The staff were well known in the community and had similar experiences as the women who took part in the projects so could understand and empathise with the women
- Working in partnership with other organisations
- Used existing relationships with other organisations such Children's Centres and Oxfordshire Mind
- Shared resources with partner agencies
- The Asian women's group developed a further understanding of the issues that women face
- Potential for future work to improve health and wellbeing of Asian families

# Limitations of the project were:

- The limitations of time for the project delivery. High demands on women to deliver on time.
- Being from the same community can also be a limitation
- Short term project may have raised expectations of women
- Focused only on three issues around health
- There are too few survey responses (101) and too few responses to certain questions to draw inferences that relate to the whole population of Asian woman in Oxfordshire.

# Important messages from this study

### **General Practitioner**

- 1.1 A person's language, culture and religion need to be considered on registration with a GP.
- 1.2 Cultural awareness training for all frontline staff at GP surgeries e.g. training for receptionists.
- 1.3 Systems put in place where a person who cannot speak English can alert the health staff and can be called back by interpreters speaking their language.
- 1.4 More resources needed across health and social care to provide interpretation.
- 1.5 General practitioners needs to be aware which medication is Halal.

#### **Access to Services**

- 2.1 Travel arrangements need to be considered for women who have to travel in from different areas.
- 2.2 GPs need to deliver surgeries in different areas so they can be accessible to women who use public transport (perhaps ways could be found to encourage GPs to hold some clinics in appropriate community centres with sufficient privacy).
- 2.3 The extended family members need to be considered and in some cases support for husbands and close family members needs to be in place.
- 2.4 Information needs to be translated in different languages and verbalised to women around GP access, mental health and Domiciliary Care.

#### **Mental Health**

- 3.1 Access to GPs needs to improve (starting with the receptionist training at GP surgeries?)
- 3.2 More awareness in Asian communities around Mental Health issues so that Mental Health support provided in local Asian communities by local people
- 3.3 Open access, early intervention approaches for women at risk of depression e.g. as a result of a major event in life
- 3.4 Tailor made services are needed to suit the needs of the Asian community suffering from mental issues.
- 3.5 Health service to provide support groups to enable the families to develop confidence and self-esteem to get support, and to challenge the prejudices and stigma in the community around mental health issues.

# **Domiciliary Care**

- 4.1 More awareness of care managers for the support needed to care for the elderly.
- 4.2 More awareness and clarity around direct payments and how they can be used to overcome literacy barriers.
- 4.3 Support with paper work when offering personal budgets or direct payments.
- 4.4 Religious and cultural sensitivity when providing care for the elderly or disabled.
- 4.5 Care agencies to work closely with Asian families to provide care that is tailored to the needs of that family.
- 4.6 More support and information in community languages for families caring for their elderly relatives at home.

# **Conclusions and Key Recommendations**

Public health organisations need to work collaboratively with local Asian-communities, to Identify gaps and barriers in services and to support the communities. They need to:

- 1. Work to overcome the barriers Asian families face when accessing GP services.
- 2. Ensure early identification and prevention measures in place for Mental Health issues and to reduce stigma.

3. Identify needs of the disabled and elderly and put culturally appropriate care packages in place, including support with accessing services and eligible payments.

Asian women reported facing many barriers to accessing health services on a daily basis. These issues are mainly related to the location and having to travel in from different areas on public transport. In addition the women faced language, cultural and religious barriers. Language is one of main barriers in accessing their GP services, with a shortage of interpreters. GPs need to be made aware of the key issues such as women feeling embarrassed to consult with a male doctor or nurse and religious events such as fasting in the month of Ramadan and the need to have Halal food and medication.

Data from the GP questionnaire analysis shows around 50% of Asian women use GP services at least once a month – and many are prescribed antidepressant medication. This needs to be probed further with a view to looking at preventive, early intervention approaches.

Further educational work is needed within the Asian community on Mental Health to overcome the myth and stigma and give good clear information on signs to look out for and provide signposting on what to do and where to go – e.g. publicise telephone numbers where they can call someone who can speak their language to have a confidential discussion or arrange a meeting. More awareness within the health and community sectors around mental health issues in the Asian population is needed to overcome internal and external barriers. Public health services need to take more preventive Mental Health measures and have ways of identifying at risk individuals and families. Many women isolate themselves from their own communities and the wider society. Lack of awareness and community services mean women suffer in silence.

With regards to domiciliary care, lack of information about direct payments and personal budgets, and the cultural expectations of caring for elderly at home by family members create barriers to individuals accessing home care services. More needs to done to break down some of the barriers when planning services for the Asian families. Cultural awareness training and interpreter services are also needed.

In summary, there is still a long way to go for Health and Social Care services to develop the cultural awareness and work in partnership with the Asian community. There is potential capacity and expertise to be gained by working with religious institutions, voluntary groups and other cultural organisations to support the Asian community to be able to use all three services more effectively.

- The need for educational work within the Asian community to reduce stigma and promote understanding about mental health issues. The call is for the provision of more community outreach to:
  - support women from the Asian community who have had experience of mental health issues themselves, so that they in turn can support isolated women in their own homes and provide information and signposting to services;

- work with the wider community and facilitate support groups to eradicate cultural myths around mental illness.
- 2. The provision of culturally aware GP surgeries and drop-in appointments in accessible centres with a less formal structure (e.g. clinics in appropriate community settings or children's centres), and support to overcome the barriers Asian women face accessing GP services, such as women feeling embarrassed by consulting with a male doctor, or the need to have Halal medication.
- 3. Better information and support to enable the take up of help available for families caring for family members at home (including direct payments and personal budgets). There is a need for more research to identify the needs of the disabled and elderly and for training to put culturally appropriate care packages in place.

End

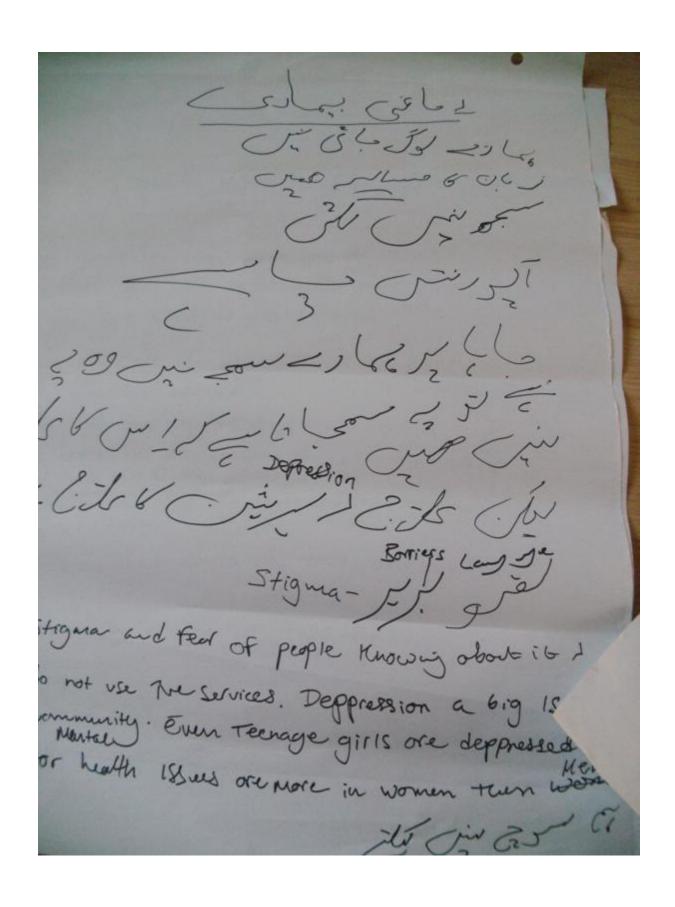
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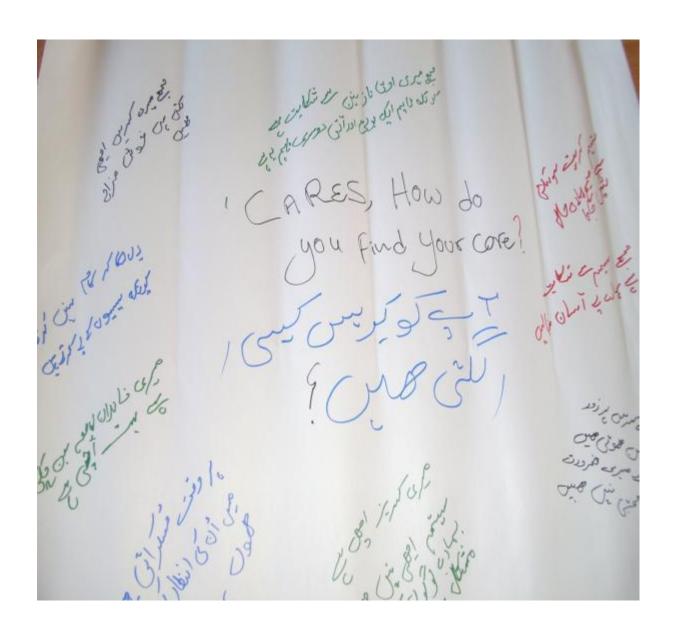
  <a href="http://www.nhs.uk/Livewell/SouthAsianhealth/Pages/Overview.aspx">http://www.nhs.uk/Livewell/SouthAsianhealth/Pages/Overview.aspx</a>

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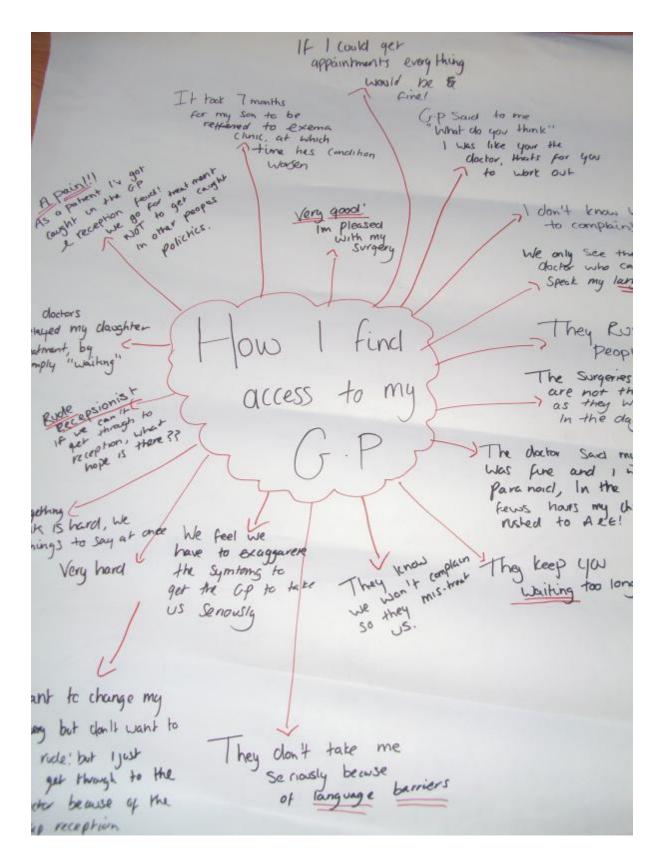
# **Appendices**



Appendix 1



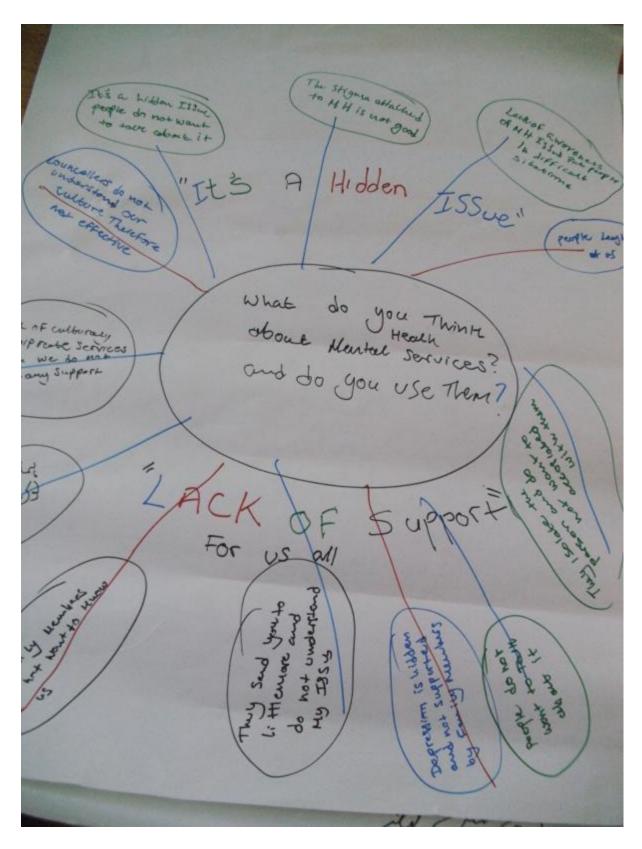
Appendix 2



Appendix 3



Appendix 4



Appendix 5

Also see attached Mental Health Stigma report 2012 (Appendix 7)



Appendix 6



# Oxfordshire Community and Voluntary Action Development Team

Tel: 01865 251946

# Mental Health Anti-Stigma Project

Email: hilary.burr@ocva.org.uk

Registered Charity No.1108504 Company No. 5363946 Registered address: The Old Court House, Floyds Row, St. Aldates, Oxford, OX1 1SS. Tel: 01865 251946

# **End of Project Report Form**

Please complete this form with reference to your own project plan. If you have any questions or concerns, please contact the OCVA Development Team.

# 1. Name of Organisation

# The Asian Women's Group

2. Name of project

# The Wonderful Women's Project

# 3. Aims of your project

- Raise awareness of stigma attached to mental health issues in the Asian community.
  - 1. Highlight the prejudice and oppression experienced by women with depression.
  - 2. Challenge some of the attitudes that prevent women talking about their experiences.
  - 3. Breaking down barriers between women that have experienced depression and bipolar disorder and those women who have not experienced it.

# 4. Output Indicators

- Explain briefly what happened, referring back to your project plan. Be as specific as possible. For example, if the plan said '3 workshops' did they all take place? Where did they take place? How many people came? Etc.
- Please include an estimate of how many individual face-to-face contacts between people with differing mental health experiences occurred during the project

The project started with two events to raise awareness of the project. The first event was in the Rose Hill area, for all the Asian community to come together and start dialogue around this taboo subject in a comfortable and welcoming environment. We had over 175 women and children come to this event.

The second event was in East Oxford a targeted approach at mother in laws and elderly women in the community. As many Asian families live in extended families and with a hierarchy in the family often the father in-law or mother-in law is the head of the family; they make the ultimate decisions in the house. Lack of understanding of the illness such as postnatal depression meant that the person suffering does not get any support instead is seen as incompetent and unable to cope with daily chores. We had over 70 mother-in laws attended and this was an interesting session. Following the two events we decided to deliver the programme in the following areas in Oxford; Rose Hill, East Oxford, Cowley, Headington and Wood farm area.

We also decided to deliver the programme in different ways as consequently families of Asian person Adult/Children. Here in Oxford tend to disengage from the rest of the community and live predominantly in self-imposed isolation. Women do not freely mix and interact with the rest of the community because they do not want their mental illness to be seen in public. Most of such women are embarrassed by their illness, women and family members and would either leave the person with the illness at home with a member of the family if there was a need to attend a social event or choose not to attend the event if it means having to come into the public domain.

To some families this is a curse and a taboo and they tend to avoid families with a known mental health issues. They tend to treat the family with disdain. Families will therefore tend to feel socially rejected and discriminated against in their own communities.

The consequences of the effects of the taboo and social stigma associated with mental health means most Asian communities:

- Mental illnesses kept hidden as far as possible and are not brought out into the public
  unless it is vitally necessary. This denies the person the right and ability to come into the
  public and be part of the community.
- The mind-set that mental illness is the result of some evil act perpetrated by the person in
- Similarly people without mental illness do not want to be associated with person with mental illness
- By withdrawing from their community and choosing not to engage with the rest of the community for fear of ridicule and discrimination. Families tend to suffer from social isolation, loneliness and associated health problems such as stress and depression for the extended family members.
- The by-product of the self-imposed social isolation is that such families are often not aware
  of the help available from statutory and other sources of support in the County and they
  tend not to access vital services that would help them.
- Families often deny themselves the opportunities to go out and interact with the rest of the
  community and consequently they deprive themselves of benefits of the wider learning and
  development that comes from networking and engagement with the rest of the society.

The sensitivity around mental health issues was identified and some careful consideration was given to the way we would deliver this project. Delivering services in the homes was vital to the success of the project in terms of getting the message across to the hard to reach women. It was agreed that the existing contacts of volunteers in the community would be used to deliver services in their homes. We delivered services in the homes in three areas; Cowley, East Oxford and Rosé Hill with weekly sessions with volunteer's often on a week day night for two hours.

This enabled the women to have discussion around:

- The impact of feelings on day to day life
- Experiences leading to those feelings, Bereavement, grief of loss of family members and past and present experiences
- Postnatal depression and depression in general
- The family dynamics, break up of relationships
- The stigma attached to mental health
- Coping mechanisms
- No blame no shame
- The clinical model of depression
- Looking after yourself

The engagement of 39 women took place in their homes.

Additionally there were two groups running simultaneously discussing all of the above issues using art based activities. Engaged with 65 women in both groups. We used glass painting, canvas painting, flower arranging and bracelet making, using the activities to attract women to the groups. Various discussions around mental health issues took place, such as feeling guilty for not being well, family members blaming and the shame of having mental health issues. Their discussed past and present stories of depression, some women were asylum seekers from Afghanistan and Somalia spoke about the trauma and impact on mental health, when they left their country and the experiences and prejudices in this country against them.

There were 41 women who at some point in their lives suffered depression and 21 women who stated that they have not suffered depression. We also had five sessions with the older community members such as mother-in laws and mothers. 23 women attended and had discussions around how postnatal depression impacts of the lives of a nursing mother. In total we engaged with 247 women and children through different approaches to raise awareness of mental health issues.

The last event was a celebration and a display of arts and crafts that had been displayed, fun, food, music and activities for children. We had 123 women and children came to the event with community members sharing their stories of mental health issues and how they overcome them.

#### **Outcomes**

#### To what extent were the project's aims achieved?

The project has achieved more than we had planned as the integration enabled families to have an insight and appreciation of the emotions and struggles of families with mental health issues and dispelled the taboo and stigma that they held against depression and other mental health.

- The integration offered the women an opportunity to freely interact with other women. This also helped families to dispel previously held myths and misconceptions about mental health and the taboo associated with this.
- The integration has enhanced networking and promoted friendship between the women and reduced the social isolation suffered by women.
- The integration has enhanced the self-esteem of families with mental health issues and increased their desire to integrate more with their community and become more socially active, which is good for their health and socioeconomic development.
- Discrimination and rejection of families with mental health issues within the community is reducing
  and this is increasing the confidence of families with metal health issues to engage with the wider
  community and society generally

Meetings were facilitated by the leader, in a group two trained facilitators. A trained crèche lead and two crèche assistants were always available to look after the children brought by the parents.

The growth of the Project was facilitated by a dedicated outreach volunteers who used social networks and community relations to "spread the word" and bring the leader into contact with families with mental health issues.

The leader also spent evenings and weekends in the community identifying and attending meetings of community groups to introduce the project. The leaders used personal social contacts and social networks to publicise the project and encouraged each person to recruit a minimum of five families.

The leader also attended the meetings of faith groups such as the community mosques and the meetings of Muslim groups to introduce the project and its potential benefits to the target members and the community as a whole.

The membership increased rapidly as the participants started to spread the word about the project and started to attend meetings with other families.

There has been a known increase of visits to the GP by Asian women to discuss depression and other mental health issues. One GP reported in the last year there has an increase of 15% of Asian women coming forward with depression.

# Describe any unplanned outcomes or achievement

The integration has enabled families of suffering from mental issues to understand that they are no different from families without mental illness and that they are "normal" and can reach the levels of achievement attained by women who do not experience any kind of depression. This has inspired the women to aspire to further education and even consider gaining employment and many have enrolled on to English classes.

The project have a ripple effect on those communities that were hard to reach with Families discussing

mental health issues openly and are raising awareness by spreading the word and offering support in their community to women who are experiencing depression.

# 5. Learning for the Future

# What further needs have been identified?

• Tailor made services are needed to suit the needs of the Asian community suffering from mental issues. We identified by working with community, in the community enable the families to develop confidence and self-esteem to get support and challenge the prejudices and stigma in the community around mental health issue.

#### Recommendations for Future work

- The needs of the Asian community with resources set aside for this type of work to take place in long term, to see the impact on Asian communities.
- Dealing with mental health issues or looking at it in isolation does not reflect the needs of the community. As short term project are scratching the surface and many families need intense support, lack that support because of timing or resources.
- The added social issues such as poverty, linked to low paid jobs, social isolation, lack of resources and language and cultural barriers needs to be considered when planning any intervention around mental health. This needs carefully planned intervention and flexibility around how it can be delivered.
- The extended family members needs to consider and in some cases support for husband and close family members needs to be in place.
- Information needs to be translated in different languages as well as verbalised to women around mental health and specifically post natal depression.

#### What lessons have you learned for future work?

Through this project we did not anticipate the scale of the work or the needs of the Asian communities. This type of work needs longer than the time given with emotional support for workers who deliver this work.

Most Asian community do not use counselling so the workers were delivering counselling services to families who are depressed through a major life event. We as a group we could have further work with some families for another six months as there is a feeling of a team of volunteers raising some very sensitive issues and not having time and resources to deal with it, in particularly in the home programmes. There is a feeling of frustration from the volunteers on the timescale.

# 6. Key Impacts - have you seen any impacts from your project in the three key areas outlined below? Please explain briefly

Increased public awareness of prejudice or discrimination against people who have experienced mental distress

The project was designed around discussions around prejudices and the oppression women experience when suffering from mental illness and depression.

The cultural myths around magical spells and being a curse were challenged. We discussed the discrimination women face with from family, culture and the wider society that leads to further isolation.

Improved social contact between people with and without mental health problems

The groups and home programmes build contact with the wider communities members. As Asian women are socially isolated the groups and events gave them an opportunity to get out of the house and develop relationships and friendships. It also provided a safe environment to discuss some of the wider issues and past and present experience linked to mental health.

Empowerment of people to speak out in positive and constructive ways on their personal experiences of living with a mental health problem

As illustrated above in the case study, the groups and home programmes enabled the women to overcome the myths and was able to discuss their experience of mental health. Many women were empowered to take positive steps in building there selfesteem and confidence and educate other women of the impact of depression.

#### Financial details

Please report your actual spending against the budget plan given in your application.

Please see attached budget

Form submitted by:	
SignedA	Date:03/02/2012
Shafique	
Print NameAziza	
Shafique	
Jilli Ique	
Position in OrganisationTheASIAN Women's	
Group	

Please return this form to Hilary Burr by 31st January 2012 hilary.burr@ocva.org.uk