

### Who Nasa Begum was



Nasa Begum made an important contribution to the understanding of the experiences of disabled people, and campaigned tirelessly for the right to independent living. Her work had a significant impact on the way that the health service consults and learns from patients.

Nasa worked for Mind between 1999 and 2003, initially in the “Quality and Standards” department

(now Networks and Communities) and then moved to the Policy and Campaigns team (External Relations department). Nasa brought within Mind not only valuable expertise and incredible passion, but also greater awareness of how a physical environment can be disabling.

Nasa Begum sadly passed away in 2011, but in addition to her already extraordinary contribution, she also left a lasting memory in a legacy to Mind that enabled us to support local Minds in developing projects to empower women, building on their own talents and strengths, to become inspirational for the wider community.

Thank you Nasa for having showed us all that no disability or discrimination can stop us from living our life to the full and achieving our goals in life if we are brave enough to fight for it and make our voices heard.

### What we did with Nasa's legacy

In May 2013 Mind launched the grant fund opportunity supported by the legacy left to us by Nasa Begum.

A total of £45,000 was distributed through the grant. Five local Minds benefited from it and were able to deliver project that directly supported south-Asian women, giving them an opportunity to come together, share their experiences, and discuss how to maintain positive wellbeing within their families and communities.

In line with Nasa's continuous efforts to promote collaborative working, we strongly encouraged local Minds to work in partnership with other organisations, including from outside the mental health sector. All five projects embraced this approach and truly built on existing community assets, which also increased the sustainability and lasting legacy of the local projects.

A short summary of the achievements for each projects can be found below:

## Mind in Bexley

The project aims were to work with, develop, train and support community members as co-researchers, in order to record the narratives of 15 members from the South Asian community and to discuss mental health needs with a focus on 2<sup>nd</sup> generation experiences.

The research set up an Advisory group, created and developed a partnership with the University of Kent and Christchurch University and provided workshops and training sessions to explore some of the principles of the research and ethics and designed a questionnaire.

In addition, the group undertook a **comprehensive literature review** with community members on the themes of the project (available in Annex 1), developed and refined a research questionnaire and piloted interviews with 15 community members.



Project partners worked with academic researchers from the University of Kent and Christ Church University and 6 community members as co-researcher who worked on all aspects of the project. The philosophy that underpinned the research was the belief that it is necessary to engage with human stories, which tell us how people have felt about, made sense of, and coped with distress, if we are to fully understand how services can be improved for those experiencing mental distress and other forms of stigma and discrimination. As recommended by Alison Faulkner (2004), users were involved from the start of this project and the ethical guidelines proposed in Faulkner's work have been followed as far as practicable given the limited resources of this pilot project. Service users were involved in all discussion of research protocol, design, ethics, translation etc in this pilot project. As part of this, individual lecturers from the University of Kent and Christ Church University, an oral historian from Oral History Matters and staff from Mind in Bexley have provided intensive support, guidance and training to those involved in the scheme.

A thematic analysis of the interviews then resulted in the co-production (academics and community members) of an audio and visual exhibition which was displayed at Queen Marys for one month in April 2015.

As a result, of the findings Bexley Mind have worked with women from the community to set up a new entity entitled the **Bexley Women's International Group** which will focus on well-being initiatives for South Asian residents of Bexley.

A significant amount of time was spent working with the South Asian community and the wider Bexley community on this project. Bexley Mind delivered roadshows to raise awareness of the scheme and had open days at Mind to encourage individuals from the community to access the scheme. They also raised awareness of the project via BVSC, Oxleas Foundation, the local Mosque and Mind Networks.

Six community members received training and support on ethics, the interview process, oral history techniques and the research process thus improving their confidence and increasing their opportunities to access further training and possible employment. Positive feedback which indicated that the project had significant impact on their confidence and self-esteem. The interviews enabled us to engage with community and improve knowledge and awareness about mental well-being and opportunities to access Mind services.

The project has also enabled community members to speak about their experiences and generating awareness in public attitudes to migration, inter-generational issues and mental health.

The ultimate aim of Mind in Bexley has been to support more truly user-led research, but it is recognised that support for this, in terms of resources, is not yet in place. This project was a first step on the road towards truly service user-controlled research with users and the South Asian community. In addition, this project has focused on the process of research as well as the outcomes – recognised as important by Thornicroft and colleagues, who report on a consultation with mental health service users who identified ‘user involvement in all stages of the research process’ as their top priority (Thornicroft et al, 2002).



This research highlights some complicated issues relating to post migration factors and second generation health inequalities. Issues including linguistic and communication problems, financial problems, housing problems, high expectations and poor psychosocial wellbeing and stress were raised in the research. Some participants also indicated that they were coping in isolation with bringing up a family amidst marital and financial

problems. Individuals also expressed concerns about leaving family members in their country of origin. The project found that parents were concerned that their children were losing cultural and religious values. Participants also highlighted concerns that their children would leave the family home resulting in loneliness in old age. As a result isolation and depression was reported as common. Findings will be exhibited in order to raise awareness.

The research indicated that Mind in Bexley need to better acknowledge the range of problems experienced by the South Asian community in Bexley. By taking a wide perspective of mental health needs and redefining recovery and services to incorporate quality of life, we can better plan interventions, taking into account the multitude of social, cultural and political factors which impact on the health of this group.

## Greenwich Mind

The aim of the project was to provide Group Therapy for this specific community group with a view to improving their mental health and wellbeing. The target was mainly to find ways to combat isolation, motivate, and empower, due to feelings of dislocation from their country of origin, and struggling to adjust life in the UK. It was felt that therapeutic psychological intervention in a group setting could prove helpful.

Through our existing Asian Counselling Service, our Asian Counselling Co-ordinator identified 2 'difficult to reach' communities, who are prominent in the Plumstead area of the Borough, the Tamil and Nepalese communities. It is known that many of the women from these particular community groups (Tamil and Nepalese) have been 'dislocated' from their country of origin, very often due to political conditions prevalent in their country of origin, which leaves many with increased mental health support needs. We were therefore very keen to provide a group-based service which would be of benefit to women within these communities in addressing their mental health support needs, and which would focus on empowerment, confidence building, and increasing self-esteem (as well as enjoyment) through participation. We sought to achieve this through the establishment of 10 group sessions for women from each of the two communities (i.e. 2 groups, one Tamil, and one Nepalese).



In order to generate an adequate number of clients, publicity materials in Nepalese/English were displayed in various community centres, GP surgeries, local authority, social service, the local NHS trust, and community settings, etc.

The response was very satisfactory and it was not difficult to generate up to 10 clients prior to beginning the group. As the group was running for the first time, it was decided that 7 clients were given the opportunity and a waiting list was prepared for the next group, which Greenwich Mind would resource due to demand.

The group was programmed for 10 weeks. Saturdays 10.00 am -12.00 PM  
It was divided into two parts 1) psycho-education, and, 2) experiential self-exploration.

All the group members were individually interviewed / assessed by the Co-ordinator of the Asian Counselling Service. Psychological assessment forms PHQ and GAD forms were filled in with a view to monitor the outcome measure at the end of group therapy.

The group was facilitated by a qualified therapist from the Asian Counselling team assisted by a helper who spoke Nepalese. Some of the topics covered are:

- ✿ Experiential self-exploration, i.e. Who Am I (meaning of your name)
- ✿ Hopes, fears, Strength, weaknesses, personal gain/ losses
- ✿ Work with positive qualities and strengths
- ✿ Tools needed to enhance the strengths.

- ✿ Strength hindrance; unhelpful thinking Style.
- ✿ Self Esteem Development; Group discussion
- ✿ Self Esteem Exploration.
- ✿ Assertion - Meaning of assertion, how to use it appropriately.
- ✿ Role Definition, including responsibilities in relation to self, family, extended family, community, wider community
- ✿ Acceptance in relation to self and others.
- ✿ Reflection - Identifying the benefits of the group work and how this knowledge can help in future.

The outcome of the group participation was very positive.

Group members were individually assessed (PHQ9/ GAD) shows significant positive changes in their wellbeing.

A culture specific social meeting was arranged at the end of summer break whereby all participants demonstrated their skills in a lucid friendly way.

The group is now on twitter and facebook, and is regularly advertised in the local Nepalese community newspaper.

The second group set up was the Sri Lankan Women's Group

Although the publicity of the project was good enough, it was difficult to generate clients who were interested in personal growth. The experience of trauma had an effect over their life and it was difficult to establish a sense of trust in them. A sense of insecurity and uncertainty is prevalent.

After identifying these difficulties, the group was structured in a way where through painting, drawing clients could express feelings. Various relaxation techniques were also part of the programme.

The programme was therefore restructured, and it was possible to generate and engage clients. It was facilitated by a highly skilled therapist who worked with body language and non-verbal communication. Psychological assessment i/e PHQ and GAD were measured in the beginning and at the end of the group.

The outcome was remarkably satisfactory. Six clients joined the group initially and four of them completed the 10 week programme (see above)

While both groups proved to be very successful, the Sri Lankan Women's Group highlighted unforeseen difficulties in establishing itself, although these were overcome, and the group successfully completed.

The Nepalese Women's Group however, has proved very popular, and as a result of the funding to begin such a Group, its success has led Greenwich Mind to resource a further Nepalese Women's Group beyond the one created from the Nasa Begum fund.

## Leeds Mind

The aim of the project was to provide peer support, counselling and art provision for Asian women within their local community and in their native language, thereby enabling them to support one other, developing skills and networks to manage their mental health and relationships.

Funding from the Nasa Begum Legacy Fund has enabled Leeds Mind to develop and expand their work with women from South Asian communities. Leeds Mind had previously worked in partnership with the Dosti Asian Women's Support Services to ([www.dostileeds.org.uk/](http://www.dostileeds.org.uk/)) to adapt the Leeds Mind Peer Support Model for delivery to Asian women in local community venues and their native language. Evaluation of the courses showed that the women gained skills that helped them better manage their mental health and interpersonal relationships and that they would not have accessed similar courses if they had been in a venue outside of their community and in English. This grant has enabled to expand and develop this programme to being city wide and to work with a diverse range of existing community groups and to provide support to South Asian women who are isolated; English is their second language and who suffer from mental health and emotional difficulties.

As part of this project, the following was delivered:

- ✿ 40 session of psycho-educational peer support group work
- ✿ 40 sessions of peer support creative arts sessions
- ✿ 60 sessions of counselling

Three facilitators from Leeds Mind were involved the initial development and delivery of this project. They are from a range of Asian backgrounds (Indian, Pakistani and Malaysian) and are able to provide a broad range of skills (group facilitation, counselling and creative skills). All have lived experience of mental health difficulties.

During the project a further six facilitators were recruited who have been involved in the delivery of this project; all have lived experience of mental health difficulties and five are of Asian origin. Four have completed the accredited training course We have received requests from two Asian men to attend facilitator training with the aim of setting up either mixed or men's group. This is being met outside this project, but will also provide facilitators who can deliver activities for (mixed) Asian groups

We identified and contacted ten organisations that support women from the South Asian community. We discussed how we could work in partnership with then to offer peer support, craft session and counselling to the women who are supported by these community organisations. These included:-

- ✿ Dosti Asian Women's Support Service (two different groups and venues across Leeds) [www.dostileeds.org.uk/](http://www.dostileeds.org.uk/)
- ✿ Khoshish Adult Social Care Asian Women group
- ✿ Hamara Project (Khushi project and Echo Centre) <http://www.hamara.org.uk>
- ✿ Sikh Elder Service [www.touchstone-leeds.co.uk/sikh-elders-services](http://www.touchstone-leeds.co.uk/sikh-elders-services)
- ✿ Bradford Mind Asian women's group <http://www.mindinbradford.org.uk/>
- ✿ The Market Place (service for young people aged 13-25) [www.themarketplaceleeds.org.uk/](http://www.themarketplaceleeds.org.uk/)

- ✿ Asha project; Asian women's project in South Leeds  
<http://www.aspiretosucceed.org.uk/>
- ✿ Bangladeshi Community Centre
- ✿ Shantona Womens Centre [www.shantona.co.uk/](http://www.shantona.co.uk/)
- ✿ Archway (young people's service) <http://www.renewleeds.co.uk/our-projects/archway/>

We have also been contact by organisations who have heard about the project and were keen to be involved in developing peer-led services for the Asian women they currently support. These included :

- ✿ Touchstone community development service (two differernt groups)  
<http://www.touchstonesupport.org.uk>
- ✿ Shakti project, Health for All (two differernt groups)  
<http://www.healthforall.org.uk>
- ✿ Well women Centre, Wakefield <http://www.wellwomenwakefield.org.uk>.  
Four Asian women's groups at Pinmoor, St Mary's Agbrigg and Balne Lane.

Dosti We have provided a range of activities at two different venues for the women who are supported by Dosti, including a mother's group in Armley, West Leeds and Dosti's Khushi group at Chapel Town Children's Centre in North Leeds.

*Dosti's mother's group, Armley*

Eight sessions were delivered including what is peer support, emotional eating, building resilience, being compassionate, meditation/mindfulness and jewellery making (3 sessions). Sessions were attended by 11 participants which included two members of staff who were interested in developing their facilitation skills, one of whom has gone onto complete the facilitator training programme. Counselling was offered to, but not taken up by any of the women.

Feedback and testimonies

- ✿ The ladies enjoyed learning about healthy eating and becoming aware of unhealthy eating habits
- ✿ The ladies enjoyed rounds and social aspect of the group 'it was nice to work one by one so we can talk and listen'
- ✿ 'I am looking forward to next session'
- ✿ The co-facilitator reported that the emotional eating session went very well and the ladies responded positively to this. Healthy food and healthy eating plate were very useful and helpful and most of the ladies took the hand-outs home to share with their families.
- ✿ The ladies were excited about jewellery making and being creative as some of them have never made jewellery.

*Dosti Khushi Group Chapeltown Children Centre.*

Craft Activities Nine Craft sessions were offered to women who attend the Khushi group at Chapel Town Children's centre in North Leeds. Activities included jewellery making, wool felting and Batik. The initial six sessions were delivered by a jewellery tutor supported by Inkwel volunteers (all of whom still access support from mental health services). Sessions seven to nine were facilitated by the Inkwel volunteers themselves.

Average attended at the session was ten, with 15 different members of the community attending the sessions. The group was made up of Asian and Arabic ladies living in LS7, LS8 and LS17 and ranged in age from 18-64 years.

Many were the women who attended this activity were isolated and almost housebound and had not been attending other Khushi group activities or the centre for some time. They soon became engaged in the craft sessions and attended the classes regularly. The craft sessions provided a relaxed and friendly environment for the ladies to bond and get to know each other. They praised each other's efforts and supported one another during the course of the sessions.

**I wasn't going to leave the house today but I am so glad I did. I'm really enjoying myself - the time has passed too quickly**

**I feel calm and happy, concentrating on being creative than anything else"**

At the request of the learners themselves, one of the sessions was dedicated to making jewellery that could be sold at a fundraising day for other members of the Khushi Group. Also at the request of the group, the craft facilitators are assisting the workers to purchase tools and materials so the centre can run their own sessions regularly. This will prove a peer-led environment where the ladies can share and learn their skills with each other.

Feedback was group members was 100% positive, with all of the group feeling 'more relaxed', 'happier' and 'very nice' during the craft sessions. The women asked if it was possible to have more sessions, more materials and more time per session.

A 7 week wellbeing course has also been delivered which included stress management, managing physical and emotional pain, healthy eating, what is mental health, what is confidence and building resilience. The course was attended by eight women. All shown an increase in the wellbeing score (WEMWBS), with an average increase of 8 points. Participants reported that the course had:

- ✿ provided them with new information about mental health
- ✿ helped them develop skills to better manage their mental health
- ✿ helped distinguish between different emotions
- ✿ socialise more
- ✿ increase confidence to deal with difficult situations
- ✿ improved self esteem
- ✿ Improved dignity and respect for me, eventually others will do the same.

A six week confidence building course was delivered to the Khoshi group and was attended by ten different women. Evaluation of the course was difficult as the evaluation forms were in English and many women did not have good written English skills. WEMWBS evaluation forms have therefore been translated into Urdu which has meant that evaluation is much easier for course participants and does not require facilitator input. Verbal feedback was also used to capture what the women had gained from the course.

- ✿ Tools to monitor my mental health and look for positive coping strategies
- ✿ New information about what mental health is
- ✿ Sharing my feelings helped me to feel better
- ✿ Gave insight into the skills I have, I have to embrace those and not compare self to others
- ✿ I am not better able to cope with emotional distress
- ✿ Everyone was really supporting and listened
- ✿ I am able to voice my feelings, which makes me feel empowered.

## Arts and Crafts (4 weeks) and Nutrition and Wellbeing (6 weeks)



These activities were requested by the Khoshish group. Ten ladies completed this course and showed an average increase in wellbeing score of 6 points. An example of the Art work created by the Ladies is shown below.



The ladies all reported that they had found the sessions on nutrition and wellbeing very useful and that it was helpful to have these discussions in their own language.

## Being able to do crafts helped me stop thinking about my problems

A five week confidence building course was delivered to women who attend Touchstone's Sikh Elders group. This was delivered at Inkwell, and was attended by 6 ladies. Deliver at Inkwell helped encouraged the ladies to access Leeds Mind Creative Arts activities – two women went on to attend these groups. Participants reported that the course had:

- ✿ Gave me confidence that I can do things
- ✿ I am better aware of my feelings
- ✿ I feel I am in better position to deal with crisis
- ✿ Quality of life has improved as I feel comfortable with myself, I am not being hard on myself to do things which I don't want to do.
- ✿ Gave me confidence to voice my feeling, which I have been struggling to express for a long time
- ✿ Having the course in our own language made it easy to participate and feel the part of the group

An additional course was delivered in collaboration with Bradford Mind to mixed group of Asian and Caucasian women

Bradford MIND operates "drop-in" style women only session on Fridays which include women from South Asian and Caucasian backgrounds. Consultation with the women and staff at this organisation identified that they would prefer the courses to be delivered in English and in a "mixed" environment. It was felt that the women had worked hard to integrate with one another and a separate project for Asian women only might undermine this progress. Group work was therefore delivered in partnership using funding from the Mind Innovation grant awarded to the Yorkshire and Humber Mind consortium. Bradford Mind is also keen to develop mixed groups for Asian men and women, and have a male group facilitator who is keen to undertake our facilitator training. His training is being funded by other sources but will provide positive links with this project.

A four week course was delivered at Touchstone Support Centre in East Leeds. This was a bespoke course which included sessions on Managing stress, feeling good with colour, emotional eating and building resilience (these sessions being selected by group members). A total of 13 women accessed the session, six were

South Asian , one Chinese and the other six Afro-Caribbean. Six women attended over 50% of the sessions including four South Asian women.

Five women completed the pre- and post- course WEMWBS evaluation; there was an increase for all women of between 2 and 18 points; on the whole the WEMWBS score for this group were low <40, and only slight increases were noted. This is not unexpected as these women are all receiving support from Touchstone for their mental health, rather than accessing a community group, as is the case for other groups we have worked with.



**I have learnt a lot about depression.**

**I have learnt some new ways to manage stress.**

**Learnt new ways to relax – I liked the meditation.**

**I liked meeting new people.**

**Good to share experiences with others.**

A six week programme was delivered as Asha which included Introduction to Group Work, Feeling good with colour, coping with Stress, Emotional Eating, Setting Boundaries and Relaxation skills. Eighteen women attending the sessions, with twelve women attending over 50% of the sessions. Seven women completed the pre- and post- course WEMWBS evaluation; there was an increase for 6/7 women of between 4 and 26 points; with one women showing a decrease of 15 points. This indicates that the majority of women who completed the evaluation showed an increase in their wellbeing during the course. All participants reported that they found the skills sessions useful and reported an improvement in the relevant skills at the end of the session.



✿ **I have learnt how to better manage stress in my life.**

✿ **I have learnt ways to manage my stress and anger.**

✿ **I have learnt how to eat more healthily and why I eat more or less at different times.**

✿ **I have learnt lots about how colour can affect mood**

✿ **I have learnt lots about boundaries with family and friends**

✿ **I have learnt that I need to set up more boundaries in my life.**

### Other achievements;

- ✿ A one hour radio slot at the local radio station Asian Fever FM helped with the promotional work. Bindu, one of the facilitators, talked about the project and how it could benefit the community. This was broadcasted on 16<sup>th</sup> March in Hindi and Urdu.
- ✿ An article outlining Nasa Begum Project has been highlighted in the newsletter at Volition this will be published in mid-April.
- ✿ A peer support conference was held in Leeds on 6<sup>th</sup> June 2014. The achievements of this project were celebrated in a workshop on Peer Support in the BME community.

### Lessons learnt and challenges identified by Leeds Mind:

- ✿ *Resources (facilitators).* There was been very good engagement by many community organisations with this project. At the start of this project we had only three facilitators who had the skills and experience to deliver the group work activities and it was initially difficult to meet demand of all potential partner organisations. This has meant that the project started slowly, but has now built in momentum. This has been aided by the recruitment and training of bi-lingual peer support group facilitators. Three women have completed the training, with a further one underway.
- ✿ *Partnerships with community organisations.* Good support and partnership working with the community organisation was essential for the successful delivery of courses. This required staff input and time from the partner (community) organisation as well as input and time by the group facilitator. For some organisations this was a challenge due to the limited resources with which they are working and meant the courses either had to be cancelled (due to lack of participants e.g Hamara and Market Place) or they were not able to engage at present (Archway, Shantona). We have maintained links with these organisations and hope to be able to work with them in the future.
- ✿ Resources in native Asian languages were needed (e.g evaluation forms) The WEMWBS form has been translated into Urdu which has helped improved the use of this evaluation tool. Translation of other resources would also be helpful.
- ✿ Counselling in native languages has not been requested by any of the women we have work with so far. When asked about what they would like ladies asked for more courses and creative activities rather than 1:1 work. We therefore requested the money allocated for counselling be used to provide additional group work activities. This was agreed and an extension granted until March 2016

There has been great demand for the peer-led skills based group work; we have had many requested from organisations that we have worked with to return and deliver more courses, as well as requests from other organisations (such as Well Women Centre in Wakefield, Northern Refugee Forum, Leeds Refugee Forum). Further funding is needed to maintain and develop this work.

We have shown that the Leeds Mind Peer support model can be used effectively to support South Asian women, and identified areas where the model needed to be

adapted. It has been essential the group work is offered in community venues that are known to be accessible and safe for South Asian women. The need to travel across the city to attend groups is often a barrier to women accessing support. We have also found that facilitation of groups by women who have lived experience of both mental health difficulties and of being from the South Asian community is also essential for success. We have been able to recruit and train a number of facilitators who have this experience and are therefore able to adapt standard course resources to meet the needs of South Asian women. Translation of course materials (e.g. evaluation forms) was also helpful.

There has been a lot of interest in this project and requests to expand this work to other BME communities including Eastern European, Afro Caribbean, Farsi, Refugee and Asylum seekers and to work with men and/or mixed gender groups. The work with Archway and the Market place requires additional skills as the participants will be young women. We did not have sufficient demand to set up groups working just with young Asian women, but are exploring opportunities to offer peer support to young people in groups of mixed gender and ethnicity.

We have received requests to develop a specific programme to support Asian women who are experiencing domestic violence (from a range of family members, not just spouses). We will explore the suitability of using the Freedom programme to support Asian women, or adapt the programme to fit with the peer support model and the needs of Asian women.

## Westminster Mind

Westminster Mind delivered the project in partnership with WAES (Westminster Adult Education Centre) MRC (Migrants Recourse Centre) and MBS (Marylebone Bangladeshi Society). The core offer consisted in establishing a support group for Asian women coming together to do needlework and sewing while at the same time being able to explore issues relating to their wellbeing.



**RAGS TO STITCHES**

Needlework and Sewing Group  
Taster Sessions

MBS Centre 3 Boscobel Street London NW8 8PS  
10 December at 11.30 am and 1.30pm

Would you like to do something creative,  
learn sewing skills and make friends?  
Then come along and find out about our sewing  
workshops

To Find Out More Call:  
Eva 020 7259 8100 or Sylwia on 020 7834 2505

This project has fostered positive links with other local BME organisations and under-represented groups.

Uptake was not been as robust as anticipated following the original taster with 5 participants enrolled at start of project. This increased steadily over subsequent weeks. Another taster session was planned for mid-February and the project was re-promoted through mail out and phone calls to BME organisations and other providers.

After promoting the group, we had more learners participating, (11 in total). The workshop had learners from different levels (beginners, intermediate and advanced), and they were all engaging and helping each other.

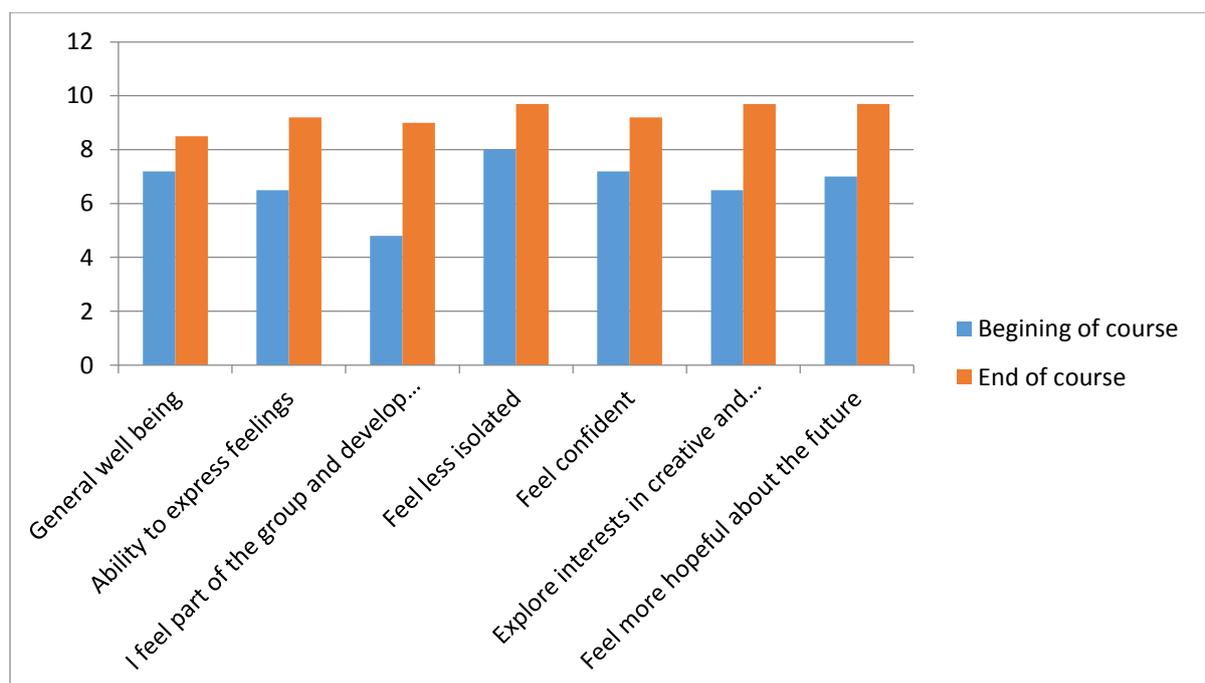
All participants now seem very engaged and happy with their progress and they were very proud showing to each other the product of their work.



Assessment forms were completed by participants at the first three sessions and the last two to monitor change. The assessment form was asking participants to indicate where they would place themselves at the following areas:

- ✿ general wellbeing
- ✿ ability to express feelings better
- ✿ feeling part of a group and developing a connection with others
- ✿ decrease isolation , increase of confidence
- ✿ exploring interests in creative and artistic activities
- ✿ feeling more hopeful about the future

Results of the analysis are captured in the table below:



## Suffolk Mind

The project was conceived as a partnership between Suffolk Mind and the Bangladeshi Support Centre and was delivered as such. Local support was received through a larger number of local organisations including Karibu African Women's Support Group, Suffolk Refugee Support, Suffolk Wellbeing Service (Norfolk & Suffolk NHS Foundation Trust coming together for the final Feeling Good event, which gave participants direct contact with relevant services – and also allowed those organisations a learning opportunity in working against the discrimination which acts as a barrier to people accessing services.



The partnership between Suffolk Mind and the Bangladeshi Support Centre enabled the project to achieve the following:

- ✿ Enabling women whose life circumstances may have put them at risk of social isolation, to access outreach support and events where they could meet up with other women, who have shared lived experience of mental ill health, shared cultural identities and in some cases were victims of domestic abuse.
- ✿ Outreach workers supporting women to access available statutory and voluntary services for people who feel isolated, stressed or lonely. Both events enabled women to find out about and have direct contact with services which support good mental health and reduce social isolation. Facilitating social contact with other women with shared experience will have reduced the likelihood of the women accessing the project developing mental health problems and increased the likelihood of their staying well.
- ✿ Delivering outreach work using *The Qur'an & Emotional Health: An Introduction* to raised awareness of which services and support are available and provided information on the signs and symptoms of mental health

problems and guidance on what to ask GPs. Where appropriate, outreach workers gave copies of *The Qur'an & Emotional Health* to women accessing support, and the booklet was also given to all women attending the Bangladeshi Support Centre's Sister's Circle; all attendants at both health awareness raising events: the PITA festival in May and the Feeling Good event in October, which brought women accessing outreach, voluntary and statutory sector groups together under one roof to celebrate the culmination of the project.

- ✿ Involving women who experience discrimination both as people with lived experience of mental ill health, and as people who experience significant barriers to accessing health and support service for cultural and ethnic reason, helped to support them in a way which accounted for these barriers. Providing information for them in way which was culturally appropriate – both through working in partnership with local community organisations and through the provision of copies of *The Qur'an & Emotional Health* – was an effective and appropriate way to address these barriers. There is still some learning to take place within statutory health services, but a start has been made towards this aim.

Women from diverse communities and with experience of mental health problems had the opportunity to take part in discussion forums and in organising events which address emotional and mental health.

Our project outcomes were to ensure that 150 women of Asian and BME origin of Muslim faith in Ipswich had:

- ✿ Taken part in meaningful engagement and discussion on how to improve and maintain good emotional and mental health.
- ✿ Each received a copy of *The Qur'an & Emotional Health: An Introduction*, which addresses emotional and mental health in a way which is sensitive and relevant to their cultural needs.
- ✿ A better understanding of how to access services which meet their needs.
- ✿ A better understanding of how to reduce the risk of developing mental ill health.
- ✿ Stronger connections with other women experiencing similar issues and concerns.
- ✿ Stronger connections with community based organisations which can provide the information they need to

**মহিলাদের মানসিক স্বাস্থ্য (ইমোশনাল হেলথ) এবং সুস্থতা**

এশিয় এবং বি এম ই (BME) মহিলাদের মানসিক প্রয়োজন  
জানবার জন্য এবং এ বিষয়ক তথ্য, পরামর্শ ও দিকনির্দেশনা  
আদানপ্রদানের জন্য মহিলাদের প্রসার প্রকল্প (আউটরিচ প্রজেক্ট)  
কাজ করছে।

- আমরা আপনার কথা শুনবো এবং আপনার মানসিক দ্বাধের প্রয়োজনের কথা জানবো।
- মানসিকভাবে ঝিকরে সুস্থ থাকা যায় সে বিষয়ে আমরা তথ্য পরামর্শ বিনিময় করতে পারবো।
- যে সমস্ত প্রতিষ্ঠান দুচ্চিত্তা এবং মানসিক স্বাস্থ্য বিষয়ক সেবা প্রদান করে তার জন্য আমরা সুপারিশ করতে পারবো।
- ডাক্তারি এবং মনোযোগ সংক্রান্ত সার্ভিস আর কি সেবা দিতে পারে তা আমরা ব্যাখ্যা করে বুঝতে পারবো।

বিনামূল্যে গোপনীয় এবং মানসিক সুস্থতা বিষয়ক যে কোন পরামর্শের জন্য  
যোগাযোগ করুন।

টিনা অথবা শাব্বরা  
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[tina.ali@bscentre.org.uk](mailto:tina.ali@bscentre.org.uk)  
[shavra.begum@bscentre.org.uk](mailto:shavra.begum@bscentre.org.uk)  
[www.bscentre.org.uk](http://www.bscentre.org.uk)

**Suffolk Mind**



Bangladeshi Support Centre

empower them to engage in mainstream services.

- ✿ Access to counsellors from Suffolk Mind and Karibu African Women's Support Group who have received training in how to support people of Muslim faith with their mental health needs.
- ✿ Had the opportunity to meet with other women of Asian and BME background who wish to discuss and gain a better awareness and understanding of what it means to be mentally and emotionally healthy.
- ✿ Taken part in events which connect them with their heritage and identity, given them opportunities to take part in therapeutic creative activities and meet the need for a sense of belonging.

At the culmination of the project, the two outreach workers at BSC had provided emotional support, information and guidance to over 344 women over the course of the year.

400 people attended the Bangladeshi Support Centre's PITA Festival (a traditional celebration of the rice harvest in Bangladeshi) in May, 38 of who were women who accessed physical health checks, had a free Indian head massage and took away a copy of *The Qur'an & Emotional Health*.

86 women from Kurdish, Bangladeshi and African communities attended the Feeling Good event on October 15<sup>th</sup>. The women attending the event took part in relaxation exercises, games and social activities; discussed the emotional needs which must be met to secure good mental health; shared food they had prepared and brought along for the day; spoke to workers from services which support mental health – including counselling, befriending and one-to-one support - and reduce social isolation; take free copies of *The Qur'an & Emotional Health*.

At both events women were able to look at and discuss the Bangladeshi Support Centre's *Curry & Culture* heritage project which celebrates Bangladeshi cultural heritage.

The project activity benefited people of Asian and BME origin who experience stress, anxiety and depression and were able to access support, information and guidance through the Women's Outreach service.

There were also a number of women who are first generation immigrants with refugee status who benefitted through accessing the outreach service and attended and took part in the second event.

Both groups experience discrimination in the form of cultural barriers which prevent them from accessing mental health services to support their needs – having the opportunity to speak to other people with similar experiences and take part in activities which promote wellbeing and awareness of services which can support their needs.

## Annex I

### South Asian intergenerational issues and impact on mental health/well-being

Palmer, D, Williams, I, Rahmen, R

#### **Introduction**

This literature review seeks to consider some of the social and cultural issues that affect the mental health and wellbeing of people of South Asian heritage living in the UK. Here we include both the first, second and following generations of British South Asians. Literature referred to has been selected for its relevance to understanding how intergenerational and family dynamics impact upon mental health and wellbeing and include studies from North America as well as European countries.

An important point to make at the outset is that 'South Asia' is a heterogeneous region which includes Bangladesh, India, Pakistan and Sri Lanka. These countries are themselves heterogeneous comprising different language, cultural and ethnic groups. These communities are also diverse in terms of wealth, class, religion, demography and geography. Some of the research cited below is based on data from large groups of 'South Asians' and some aggregates results from the different countries and areas of the sub-continent. Other research is closely directed at clearly identified groups such as Kashmiri women (Shoaib and Peel 2003) while other studies divide South Asians by the cross-cutting category of religion and, for example, compare Hindus and Muslims (Sonuga-Barke and Mistry 2000) or focus on one religious group (Pilkington et.al. 2010).

Greenwood et. al (2000) who carried out qualitative research with South Asian in-patients in mental health settings, have questioned the value of the category 'Asian' altogether. They challenge the category as they argue it ignores the effects of geography and cultural heterogeneity but also on the grounds that migration history makes for significant differences between people born and raised in the UK and those who migrated from the sub-continent. 'South Asians' broadly defined have migrated around the world and their 'culture' has been studied in many different contexts. Ahmed and Lemkau (2000) for example have studied the effect that South Asian culture may have on primary care in the US and they argue that consideration of the communitarian family values in South Asian families, religious beliefs and education levels and non-verbal communication differences are important. These broad categories could be applied to all communities however and it could be argued that practitioners should always be alert to these expressions with any client, their family and community. Ahmed and Lemkau consider the degree to which clients and their families are acculturated to where they live and emphasise that it is part of any health care practitioners role to try to determine the balance between the values of countries of heritage and countries of residence and to act accordingly.

Keeping heterogeneity in mind however, South Asian communities in the UK and in countries of migration do share some important features. Firstly they share a 'migrant' experience which for many represents a 'burden' in terms of socio-economic disadvantage, a vulnerability to discrimination and racism, problems for some community members with expression in English. The burden is not equally felt by all South Asians as some are considerably more educated and materially affluent than others. In addition some cultural attitudes and traditions are shared across these otherwise heterogeneous communities and widely-held communitarian attitudes mean that individual needs and desires may be sacrificed for the good of the collective and that women may be expected to sacrifice more than men. Concepts such as *izzat* or honour and *sharam* – shame are still

potent in South Asian communities taking on different nuances through the generations. Attitudes to mental health also differ within South Asian diaspora and this literature review shows how communities and families take different attitudes to mental health and illness as well as to health interventions. Pilkington, Msetfi and Watson (2010) argued that the literature on South Asian attitudes to mental health services are influenced by several key factors these include "... beliefs about the cause of mental health problems such as biological/social-environmental views and religious beliefs, acculturation and shame/izzat." (2010:3) With these factors in mind, this literature review does not seek to provide universally applicable rules concerning South Asian communities in the UK but will instead discuss issues raised in the literature. As noted by Bhugra et. al. (2014) the process of migration can be a protracted one that roughly divides into three overlapping and arbitrary stages: pre-migration, migration and post-migration. The first two may not affect the second-generation as much as they affect the first but "the post-migration period can last for the lifetime of the individual and may well affect the next generations of descendants." (Bhugra et. al. 2014:108) The affects of migration do not just relate to the adaptive capacity of the migrant but also encompass the structural and social environment migrants find in their new country of residence and these external factors will be discussed further below.

### ***South Asian families and communities***

The family is considered by many commentators to be the appropriate level of analysis for migrant communities (see Cottrell & Vanderplaat 2011 cited in Rajiva 2013:17). Floya Anthias' concept of translocational positioning (2005) is helpful in understanding the worldview of people whose experience encompasses different imaginations of belonging and possibility. Viewed in this light, the second generation of any migrant groups has to balance different hopes and expectations; achieving this balance satisfactorily is an important component in wellbeing. Furthermore it is important to remember that identities not fixed (Penny et. al. 2009) in the first or subsequent generations and members of any family or group may have to struggle to find acceptance or negotiate a place.

As already noted, it is unhelpful to try to generalise about people sharing the highly heterogeneous background 'South Asian' but when compared to non-migrant groups it is useful to note that many South Asian families are community orientated and that the communities that are most meaningful to individuals may span continents. Many if not most South Asian families will reach back to countries of heritage on the subcontinent but may also reach to countries of previous migration, in Africa for example, as well to newer migration destinations across Europe, North America and Australasia. South Asian families and communities are transnational and so the second-generation of these migrant families must seek to develop identities that fit within a complex set of interrelationships that cross traditions and continents. Rashmi Singla (2005) in relation to youth of South Asian descent in Denmark notes the complex negotiations they have to make and:

"Empirical evidence indicates that both the youth and the parental generation are undergoing transformations in interaction with the highly modern Scandinavian society. There are changes in the intimate partnership patterns among the South Asian youth, which are neither like the parental patterns nor like the mainstream majority youths' patterns of partnership formation." (Singla 2005:231-232)

In a similar vein Mythili Rajiva argues that second generation South Asian have lives "... marked by transgenerational negotiations around belonging and survival." Rajiva 2013:25

- Disaggregate data – community heterogeneity
  - Ineichen (2012:246) "Handling unconventional life styles such as homosexuality in the family has received very little attention."

## ***The possible effect of the higher 'burden' borne by migrants and second generation***

Migration can carry specific burdens and represent a threat to the wellbeing of communities especially if migration is forced, as it was for the 'partition' generation of South Asian or those expelled from East African homes. Migration represents a dislocation for many but may reunite others who join previously settled family members. Adapting to a new home may mean learning a new language and facing communication problems but, especially for visibly different migrants may mean facing discrimination and racism that continues into second or following generations. Rajiva describes it thus:

“While western societies often narrate migration as uni-directional and always in the best interests of the migrating population, the reality lies somewhere between this fantasy of a better life and the daily struggles, particularly for non-European migrants, to be recognized and rewarded as contributing members of the host society. This has certainly been the case for the South Asian diaspora in countries such as Canada, where they have had to overcome both every-day and structural forms of racism that shape their work and class trajectories.” Rajiva 2013:25

While the first generation may struggle with a sense of loss of their homeland, the second generation may feel unwanted in the only place they know as home. They may feel torn between lifestyles that are offered by the majority community but which are unacceptable or disapproved of by their own family. The degree to which their migrant background, rather than 'ordinary' intergenerational conflict, affects health and wellbeing is unclear in the literature.

Reviews of studies on the 'risk factors' experienced by migrants have not shown a consensus that migration is a risk factor for mental illness. A study in Sweden for example found that family factors have a greater impact on the reported mental health of children than immigrant status does (DeKeyser et.al. 2014). It is generally assumed that behavioural and other problems experienced by the second generation relate to family or school problems rather than to migration per se (Stevens et. a, 2005) but while problems may not be the direct result of migration itself, they may relate to the subsequent minority status and other migrant 'burdens'. Belhadj et. al. (2013) similarly found little agreement in studies of the effects of migration on mental health but noted that while migration itself does not seem to negatively impact upon wellbeing, other related effects of migration might do. These include “a low socio-economic status, a non- European origin, an uncertain cultural identity of the parents, maternal harsh parenting or inadequate parental occupation, a minority status...” all of which may relate to a migrant identity in first or subsequent generations. (Belhadj et. al. 2013:373) Das Munshi et.al. (2012) reviewed literature that considered the association of social mobility with common mental disorders in migrant and second-generation groups but were unable to establish a clear link between mental health problems and the second generation. They note however that the studies they reviewed revealed that downward occupational social mobility was a common occurrence for people who migrate internationally. Ineichen (2012:245-6) to argues that socioeconomic factors contribute to mental health disorders but reminds us that some South Asian communities are doing much better than others “Here disaggregation is vital, as Indians have been shown clearly to have a higher socioeconomic profile than Pakistanis or Bangladeshis.”

Nguyen, Rawana and Flora's (2011) research based on studies examining depression among adolescents from immigrant backgrounds in Canada argues that there is no strong correlation between depression and migration background. They argue for a shift away from risk models towards more positive youth development models for immigrant youth. Kirmayer et.al (2011) however found strong evidence that some groups of migrants have an elevated incidence of psychotic disorders after migration. Their work also cites a meta-analysis that found a raised risk of schizophrenia among first-generation migrants and that even higher rates were found in second-

generation migrant groups. They note however that an increased risk also came from originating in a developing country and living in area where most of the population is black, "... suggesting that racism and discrimination have a role in elevated incidence."(Kirmayer et.al 2011:961) They conclude:

"Migration poses specific stresses, yet most immigrants do well with the transitions of resettlement. Systematic enquiry into the migration trajectory and subsequent follow-up on culturally appropriate indicators of social, vocational and family functioning will allow clinicians to recognize problems in adaptation and undertake mental health promotion, prevention or treatment interventions in a timely fashion." (Kirmayer et.al 2011:965)

### ***Stigma and community attitudes to mental health concerns***

Stigma in relation to mental health has most often been related to 'external' stigma – i.e. the stigma some group experience from outside their own communities. This has been well described in relation to Afro-Caribbean communities which have been stigmatised by linking dangerousness and violence to an assumed propensity to mental illness. In relation to South Asian communities Shefer et.al. (2012) draw our attention to 'internal' stigma and argue that some communities have internalised stigma against community members who experience mental health problems. Their findings:

"... demonstrate that the multiple challenges that may be the outcome of *both* internal and external stigma should be acknowledged and addressed by future anti-stigma campaigns.... Another, more encouraging finding for future anti-stigma campaigns in this research is that there is a considerable degree of recognition not only by service users, but also by laypersons from these communities of the existence of stigmatizing attitudes and their damage. This suggests that there is some readiness for accepting anti-stigma messages within some ethnic communities..." (Shefer et.al. 2012:541)

The stigma attached to mental health problems can be powerful in South Asian communities, as in many others, and this has been suggested a reason why Asian groups may not access counselling services. Shoaib and Peel when reviewing the literature on Asian communities' relationship with counselling note that "Research on Asian people's experiences of health services has tended to focus on why Asian people do not use certain services, rather than their actual experiences of them." (2003:88) This is an important point and it may be that services are not used because they are considered unsatisfactory rather than because they are unknown. Shoaib and Peel's research with Kashmiri women of the first and second generation (2003) depict a group of women with a sophisticated notion of their own mental state but who have not found services that meet their needs.

Stigma has also been shown to affect the capacity of carers to support family members, as they may be unwilling to share their problems with their social networks. Citing Hussain (1997), Katbamna et al. (2004) have discussed how carers of relatives with mental health problems may be particularly isolated because of the stigma mental illness carries. "The need to maintain secrecy to preserve the family's reputation, or *izzat*, often took precedence over a carer's need for support." (Katbamna et al. 2004:399) Their research with four British South Asian communities: Punjabi Sikh, Pakistani, Bangladeshi and Gujarati Hindu found similar patterns across the communities despite their different histories and social positions in the UK. Across the groups, carers relied on support from within their immediate families but support was not sufficient and "A majority of carers, particularly in nuclear and female-headed households, were isolated and struggled to provide care without adequate practical and emotional support." (Katbamna et al. 2004:404)

Pilkington et.al.'s questionnaire data from Muslim South Asians on intention to use psychological services found complex relations between generations of migration, education level, acculturation<sup>1</sup>, traditional beliefs and explanatory models of health and ideas about izzat and shame. They argue that "... the relationship between acculturation, izzat and intention was more complex than originally expected and depended on whether participants had migrated to, or were born in, the host country." Pilkington et. al. (2010:15) This research is valuable in pointing us to the importance of different generations of migrants but is limited in that questionnaires were not translated into community languages and were based on western categories of illness. The authors recognise the need to follow up their results with more sensitive studies more closely targeted on sub-sets of this broad group.

Lee Knifton's community based research (2012) with ethnic minorities in Scotland (including communities of Indian and Pakistani heritage) found that anti- stigma campaigns had largely been ineffective as they had not been sufficiently sensitive to community attitudes to mental health and had failed to because of a combination of practical issues including inappropriate language, imagery and media, and the use of western medical concepts of illness. Participants in this study were reluctant to class conditions such as anxiety and depression as illnesses preferring to consider them 'part of life'. More severe conditions were considered as 'madness' which was considered a chronic condition and which carried a permanent taint that could affect the individual and their family. The stigma resulting went beyond the individual to their extended family with negative consequences for many family traditions mostly notably those that relate to marriage. A consistent finding in this research was that "conversation and dialogue would be much more effective than just receiving information in writing or advertisements. Across the groups it was felt that this form of community dialogue or workshops would be culturally appropriate, and more effective if delivered by people from within the community." (Knifton 2012:295)

### ***Experience of Services***

Many studies have considered patterns of mental health and wellbeing services and have explored attitudes to mental illness among British South Asians (see Ineichen 2012 for discussion). Rates of diagnosed mental illness in South Asian communities are unclear and prevalence of depression are considered by Ineichen to be particularly disputed. Berthoud and Nazroo's national study (1997) found a low rate of depression among the South Asian groups they considered but high measures of stress/distress have been reported from other studies in North London (Beliappa, 1991) and Glasgow (Williams & Hunt, 1997). Muslims may have especially high rates of depression but it is likely that Muslims of South Asian descent were more likely to be unemployed which may explain ill health better than their religion alone. In addition Ineichen (2012) notes that "Racism may be one of the sources of stress, experienced particularly by women and older people, but shared by all groups." (2012:239) Racism, as already discussed, may be one of the migrants' 'burdens' but its effects may be felt in services where racial or cultural stereotyping may compromise services offered. All practitioners working with migrant groups need to have cultural competence and develop sensitivity to the different cultural needs of a diverse population. This does not mean that practitioners need to be expert in the cultures of their clients but that need to be aware of how

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<sup>1</sup> Acculturation was measured using a standard scale measuring behaviours "... suggesting greater acculturation to the host community (e.g., use of the English language), attitudes indicative of greater or lesser acculturation (e.g., feelings of acceptance) and behaviours associated with society of origin (e.g., use of Asian media)." Pilkington et.al. (2010:7)

cultural differences may play out in clinical settings. Cultural competence is necessary for developing trust and in ensuring that interventions suggested work *with* clients understandings of their health needs rather than against them. This may be particularly challenging when working with second generation migrant clients who may have assumed a mix of cultural attitudes that blend the cultures of their parent's generation with mainstream attitudes reflecting their own eclectic experiences and influences.

South Asian and BME groups in general are assumed not to be reluctant to use counselling services and this is sometimes explained by the assumption that some groups just have less interest in counselling than others (see discussion in Green et. al. 2009:319-320 and Shoaib and Peel 2003:87-89). A response to this has been the rise of multicultural counselling that allows for different cultural understanding of wellbeing but carries with it 'structural awareness' of society (Green et. al. 2009). Debates continue about the importance, or otherwise, of counsellors matching the race and ethnicity of their clients and the value of specific cultural training before working with minority groups. Pilkington et. al.'s research on intention to access psychological services (2010) showed that second generation British South Asians were more likely to access services than the first generation but notions of shame and *izzat* (honour) still have an influence on attitudes to mental illness and mental health services.

Community explanations of ill health are likely to have a powerful effects on the acceptability of services and services that focus on the individual diagnosed as 'ill' to the exclusion of the significant others around them are unlikely to be acceptable. Penny et. al (2009) found their participants, families of clients attending an Early Intervention Service for First-Episode Psychosis used a conceptual framework that recognised the family in the illness of the individual:

"Families identified the problem relationally and socially—as a failure to function as one should within the family and community. The problem was explained as either a social or spiritual-supernatural problem. Notably, it was not identified or explained in psychological or psychiatric terms." (Penny et. al. 2009:976)

The same research found that families were reluctant to accept stigmatised terms for symptoms and that this created, or added to miscommunication between service provider, client and carers.

"The most common and powerful signifier of "madness" in Urdu/Mirpuri is *pagal*, which means "a lunatic" or "crazy." *Pagal* is a stigmatized term that also indicates permanence (Wheeler, 1998). ... Thus, it may be that families avoid describing symptoms that could be received as descriptions of *pagal*. Unfortunately, this only adds to problems communicating with staff. Even when interpreters are used, there do not appear to be any less stigmatizing translations for *psychosis* than *pagal*." (Penny et. al. 2009:982)

Such misunderstandings, euphemisms or deliberate obfuscations are likely to apply in any family faced with the illness of a loved one but, especially if bracketed as 'cultural', miscommunication are likely to undermine and compromise the care a client may receive. Greenwood et. al. found that the 'Asian' patients they interviewed shared many of the same concerns as other majority population in-patients and standard 'good practice' would have improved their experience. They were open to Western models of mental health and combined these models with non-Western ones. Above all the carers were less interested in theories than in coping with the effects of mental illness (Greenwood et. al 2000:406).

### ***Intergenerational conflict and dispute***

As much of the research discussed here has already made clear, family and community mores change over time. In two generations living as a minority group migrant communities will have developed in ways that differ from how they would have done had they stayed in countries of

heritage or indeed in former countries of settlement. There is no automatic relationship between migration and increased personal freedom and migrants and migrant communities do not necessarily reject traditional norms on migration. Many in fact, draw increasingly heavily on traditions and practices in order to maintain a sense of themselves and a sense of cultural authenticity away from home (see Baumann 1996 for example) In Gerd Baumann's study of communities in Southall, West London, Baumann notes how social norms have been created in transnational communities that may have more relevance to the social norms of an older generation and that "the 'traditional' *Asian culture* which young Southallians have to assess is that which their parents construct for them ..." (Baumann 1996:153 italics in the original). In this study, young British Asians described visits to Pakistan or Bangladesh where they were shocked by the modernity of family life. It is important to remember that all families and communities react to the pressures and opportunities they find in society in ways that are relevant to them. Generalisations may be dangerous and misleading.

Autonomy with family and community is one point of tension within families and in van Bergen et. al.'s study of suicidal behaviour in women of South Asian-Surinamese, Turkish, and Moroccan women living in the Netherlands, two narratives of autonomy were identified. The first was described by women of the first migrant generation and related to a lack of autonomy and a sense of powerlessness. The second narrative, expressed by the second generation however related to a clash between the family and its traditions and the young woman's sense of autonomy. Van Bergen et. al. conclude "We also observed that the first generation of rural immigrants in the study had less awareness of autonomy compared to the second generation. This suggests that awareness of autonomy may increase over generations, and an upbringing amidst a different host society may foster the recognition of autonomy." Van Bergen et al (2012: 83) This sense of 'awakening' in the second generation seems to be absent in Shoaib and Peel's account of first and second generation Kashmiri women's perceptions of emotional needs:

"For the UK born, the four main issues that caused distress were: family disputes, marital conflicts, intergenerational conflicts and financial problems. The evidence suggests that there is not much difference between issues that cause distress for both groups, apart from migration (high on the list for Kashmiri born)." Shoaib and Peel (2003:90)

The problems that upset the balance in these families crossed generations:

"Many participants talked about disputes between families caused by various factors, including different ideals, broken marriages or even children's marriages. These disputes generally involved other members of the family and caused prolonged rifts and divisions within and between families — disputes which would, in some cases, continue into the second and third generations." Shoaib and Peel (2003:90)

"Irrelevant of age, both groups felt (due to the interwoven social and psychological gaps between generations) that intergenerational conflict was a cause of distress, with both parents and children experiencing emotional distress as a result. It was felt that views, beliefs and morals frequently clashed and thus communication was difficult because of the different social, educational and cultural environments that they had been raised in." Shoaib and Peel (2003:91)

As in many communities staying silent is a coping strategy to avoid confrontation. Speaking about the strange behaviours of the mentally ill may be construed as disloyalty so hiding one's own distress or the distress of others may be a way of maintaining the appearance of normality.

"The fear that speaking to anyone in the immediate or extended family or community would complicate issues within the home environment and 'make things worse for them' led them to 'accept things as they were' and just 'live with it'. There were some elements of fear and concern

that they might be ostracised and socially isolated if they spoke about their problems. Honour (*izzat*) and shame (*sharam*) are important concepts within Asian culture and are expressed through the actions of women more than men. They are linked to 'issues of morality, social standing and respect in Asian societies' (Yazdani, 1998). To speak out would be dishonouring the immediate and extended family. Talking about 'it' would affect their parents and family's *izzat* (honour). Shame (*sharam*) would be brought on the family name and on the family's social place within their community. For some women, this would have implications for future generations of the family." Shoib and Peel (2003:91)

### **Gender issues**

It is often assumed that balancing cultural traditions with engagement in western society may be harder for women than for men. Women may be more isolated than men especially if they are in communities where women are mostly employed in the home. Some women may not enjoy sufficient social support and this may apply especially to newly migrated women who are having to cope with the loss of home and with learning how to manage in a new setting.

In Katbamna et. al's study with carers "Female carers in all four communities generally encountered greater difficulties negotiating and organising support from formal agencies because of language and communication difficulties, and a lack of knowledge about health and social services. Female carers in the Bangladeshi community encountered additional obstacles in seeking and accepting help from informal networks and formal services." (Katbamna et. al. 2004:404) Soorkia et. al. (2011) however found that the women in their research were more positive about seeking psychological help than men; their study included participants born and raised in the UK from across South Asia.

Extended families, where three generations or more live together, are typical of some South Asian communities and are considered likely to produce well-balanced children (see research cited by Sonuga-Barke and Mistry 2000:130) but they may be problematic for other family members. Family structures have complex effects on the wellbeing of individuals within families and Sonuga-Barke and Mistry's research attempts to understand the relevant factors. They considered Hindu and Muslim families living in UK communities and they compared the mental health of grandmothers, mothers and children living in extended and nuclear families. They found that while extended families were beneficial to the wellbeing of grandmothers and children, the reverse was true for mothers. Sonuga-Barke and Mistry explain this because of "The extra burden associated with the demanding tripartite role of mother, wife and daughter-in-law, adopted by these women" (2000:138). Further, they suggest that tensions between the different generations within extended families place more burdens on mothers "experiencing confusion over personal and cultural identity or a sense of isolation from other members of the family." (2000:138). Social factors may have an effect on these family dynamics as Sonuga-Barke and Mistry's work showed the Muslim mothers having worse mental health than their Hindu counterparts. They argue that this may be explained by the Muslim mothers being generally younger and less likely to be in paid employment. Muslim women were also more likely to be living in more traditional families. In this case communities that relied exclusively on community and family resources and which were reluctant to call on the support of people or institutions outside their immediate group placed the greatest burden on the care-givers, usually women, within their group. It may be extrapolated that care needs that are stigmatised and which could bring shame or dishonour on the family will be shared with a still smaller group within the family, producing an increased burden on carers who may already be isolated and overstretched. Here cultural distance between the self and mental health services (Soorkia et. al. 2011:619) may also reduce available support.

Men's mental health issues and need for social support have not been studied to the extent that women's issues have according to Ineichen (2012:241) and may represent an unmet need that will have wider community effects.

### ***Implications and Recommendations***

The discussion above describes a picture of community and family resilience in dealing with an often hostile environment. In some families the burden of caring may fall disproportionately on some family members. Health practitioners need to find ways to gain the trust of communities that are defensive and anxious about losing autonomy and cohesion. GP's and other practitioners need to be more culturally competent and more sensitive to needs of carers and other community members who may be in need of help and who may be isolated even within their communities. (Katbamna et al. 2004:405) Ineichen (2012:242) has argued that GP's face particular problems in managing the mental health problems of their British Asian patients and he cites examples of Asian patients receiving shorter interventions for depression than their white counterparts; in other cases GPs have failed to diagnose at all.

Engaging with some communities can be difficult and it is no coincidence that many of the research projects drawn on here relied on English to communicate with research participants. Despite having a female community member who shared a heritage and a language which the research subjects Tabassum et al. (2000) were not able to interview one-to-one with women but instead carried out interviews with all the adults in the family. They note that the women in the groups were prepared to disagree with the men in the group but even so the group discussion must have inhibited conversation to some extent.

It is clear that new ways of communicating within and between communities is required that can allow a freer form of discussion between majority and minority communities without either side feeling judged or intimidated. Knifton et.al. suggest the community conversation model:

“The reduction in blame and increased recovery optimism suggests that a community conversation model has the potential to engage communities and promote a culture of greater openness and acceptance towards mental health issues. Whilst further research is required, it indicates that community development approaches which construct shared meanings and understandings may be more valuable than top-down public education approaches.” Knifton et.al. (2010:503)

As Penny et al. write “... shared, acceptable understandings” (2009:983) of the needs of communities members are essential if health practitioners are to be able to support families and relieve them some of the burden that mental illness places on families and carers. Care has to be built on this shared understanding and cooperation in any interventions to be offered. If it can be agreed that South Asian cultures are collectivist then a collectivist solution is required which applies to research as well as to service provision (Tabassum 2000:179).

When faced with the illness of a loved one, families, no matter their origin or ethnicity, they want the best for them. The response of South Asian families to the baffling and distressing behaviour of the mentally ill is the same as that of any family and while explanations for the illness and ways of dealing with it may differ above all, families want an end to those aspects of the service user's behaviour that are most difficult for them to understand or are most important to them. Greater openness and responsiveness between family and service providers may be a way forward and opening the discussion before a crisis strikes may build trust and ease later conversations.

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