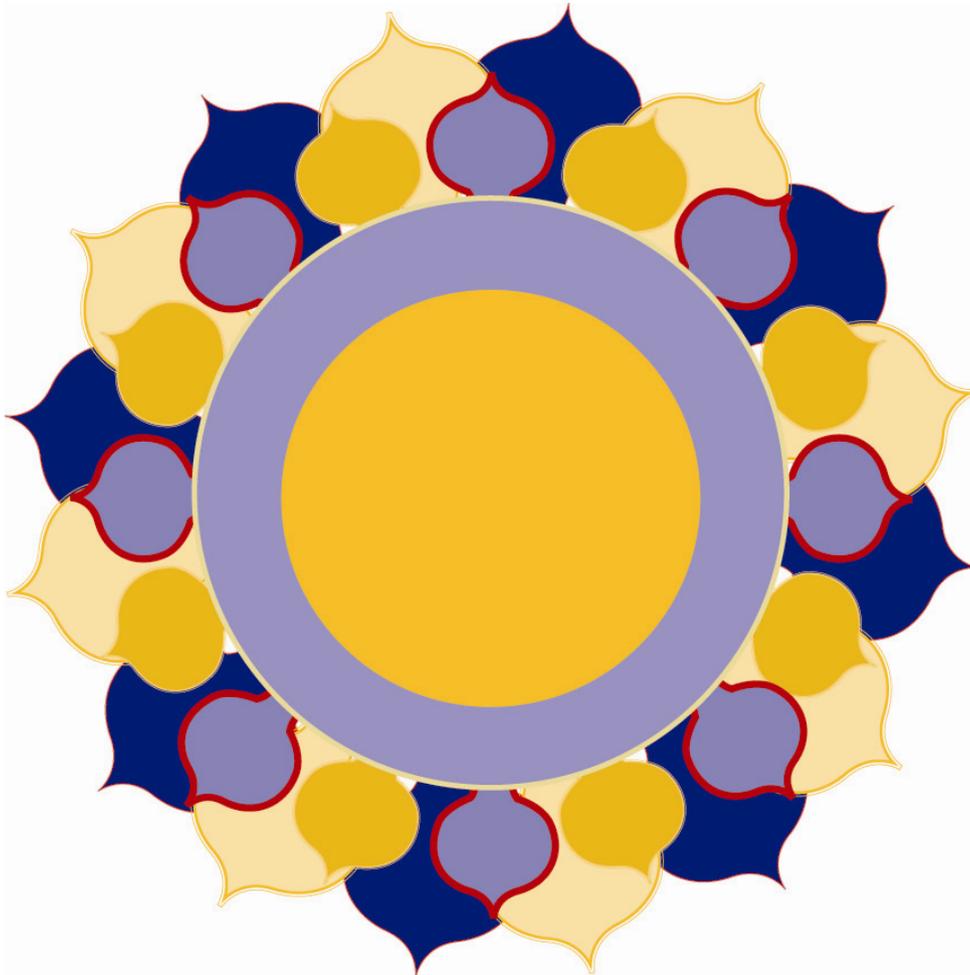


Sharing the Routes to Recovery

Report from the Minority Ethnic Mental Health Project



Outside the Box Development Support
March 2008

Sharing the routes to recovery: recovery and people from Black and Minority Ethnic communities in Edinburgh

Report from the Minority Ethnic Mental Health Project

Background

About this report

This report has come from a project looking at the experiences of people from black and minority ethnic (BME) communities in Edinburgh. The project was initiated by the National Resource Centre for Ethnic Minority Health (NRCEMH) and Scottish Recovery Network (SRN), both of whom are developing awareness about recovery for people from BME communities. The project is funded by the National Programme for the Improvement of Mental Health and Wellbeing through NRCEMH.

The project brings together 3 smaller projects, based at the NHS Lothian Minority Ethnic Mental Health Project, Men in Mind and Saheliya, which is a women's project.

There are also reports covering the other parts of the project:

- Celebrating Friendship and Diversity: recovery and men from Black and Minority Ethnic communities in Edinburgh
- A New Beginning: Recovery and ethnic minority women in Edinburgh
- Finding Strength from Within: Report on three local projects looking at mental health and recovery with people from some of the black and minority ethnic communities in Edinburgh.

This report describes the points raised by people who are in touch with the Minority Mental Health Project and have used mental health services.

We hope that this report will be used in many different ways.

- NRCEMH and SRN will be able to draw on the experiences and ideas here when developing work across Scotland in the future.
- NHS Lothian and in the City of Edinburgh Council can draw on the experiences of people from BME communities in Edinburgh as part of their on-going work and development of future programmes.

- The Minority Ethnic Mental Health Project and the other partner projects can draw on the points raised here as part of planning how they will continue to support people from BME communities who experience mental health problems.
- Mental health services working with people from all parts of the community can get ideas about how they can develop their services to provide good on-going support and care to people from BME communities.

About the Minority Mental Health Project

The Minority Ethnic Mental Health Project is part of the mental health service delivered by NHS Lothian in Edinburgh. It is based in the Royal Edinburgh Hospital and provides a range of supports to people from BME communities who are in touch with NHS mental health services as patients or carers. It also provides advice and training to staff in the Royal Edinburgh Hospital and in the community teams, to enable them to give better support to their BME clients.

About Outside the Box

Outside the Box has been asked to give community development support to the projects, in a way that reflects the circumstances of each one.

For this project, the contribution was:

- Providing background information about the project for potential participants and as publicity about the project.
- Carrying out some of the interviews with people who use mental health services and carers.
- Providing back-up advice to NHS staff when they carried out interviews.
- Writing the report from the first set of interviews.

Over the next few months, we will be working with the projects to hold an event at which more people can feed in their experiences. We will also be feeding back to staff in the mental health services.

Experiences of the people from Black and Minority Ethnic communities

About the people who took part

Information about the project was circulated through a range of routes, including

- the Ethnic Minorities Project Co-ordinator
- the day hospitals and Community Mental Health Teams, especially those working in the 2 areas where there are higher numbers of people from BME communities
- the other partner BME mental health projects.

10 people asked to take part. Most of the interviews were just with the person who used services. Two people wanted to have a joint meeting with their main carer – for one person this was his wife and for the other person it was his mother.

The people who took part included men and women and they covered a wide age range. They came from different ethnic communities. Some had lived in Scotland since childhood, while others had moved here as adults. Most had been in touch with mental health services for many years.

People had the choice of having the discussion in English, in another language with a translator, or having the discussion with the Ethnic Minorities Project Co-ordinator or someone else in their first language. Most of the interviews were carried out entirely or mostly in English.

The meetings took place at locations which were comfortable for the people involved. Some took place in people's homes and others took place in a worker's office or at a service.

Each of the discussions focussed on a few main questions.

- What keeps you well?
- What does recovery mean to you?
- How do your friends and family help you in your recovery, or to keep well?
- What would help your friends or family, or other people you know, keep well?
- Is there anything else you think would help people in BME communities living in this area in their recovery from mental health problem?

What helps you keep well?

There were recurrent themes in people's experiences around what being well meant for them and what kept them well. Many of the points raised around what

keeps people well are similar to those raised by other people living in Scotland. They also reflect the underlying principles and good practice set out in the Scottish Government paper 'Towards a Mentally Flourishing Scotland'.

People also raised points that reflected their experience around their culture and around their experience of being a member of a minority community.

Most people mentioned the same things as keeping them well:

- their family and friends
- work or education
- having a structure to their day or week
- keeping well physically – and with it having good food
- having a nice place to live
- looking after themselves
- having options and choices
- enough money, and help with money problems if this was an issue
- supportive GP and other support from mental health services
- their faith and contact with other people through paces of worship
- ways to manage symptoms, including medication, relaxing and meditation
- exercise, fresh air
- opportunity to look towards the future
- having a balance between different aspects of life
- getting away from an anti-racist environment.

Some people liked getting away from mental health activities. Other people talked about the support they got from other people who had experienced similar problems.

Some people talked about the things they had learned to do to keep themselves well or reduce factors that made them unwell.

Several people talked about their experience of racism, and how it was hard to keep well if you felt you were living in an environment that was hostile.

Some people talked about how contact with people, including staff in services who understood their culture and background was an important part of being well, and especially the Ethnic Minorities Project Co-ordinator. They also talked about how services which appeared to take no account of cultural diversity could make things more stressful or difficult.

“Getting out of the house for coffee or to a library, meeting friends.”

“Attending meetings and praying at the mosque once a week.”

“Attending Sikh Temple where I feel a sense of belonging and social networking supports my recovery.”

“Making time for prayer and mediation.”

“Doing creative things such as sewing – on my own or with friends. Making beautiful, colourful clothes that make me happy and make other people happy.”

“Medication – helping me manage the painful feelings so they do not overwhelm me.”

“Getting away from tense situations – I feel the panic starting and cannot cope, so I have learned to just walk away.”

“The roles that I have in my life – mother, wife, sister, daughter, colleague, friend – are part of being well and keep me well. But they also bring their own pressures. Sometimes those pressures get too much. But in our culture, you can't say that.”

“Thinking positive thoughts and caring for my daughter helps me feel good.”

“Sometimes it is hard to stay well when it feels people are not listening, or are making assumptions about me because of my cultural background.”

What does recovery mean to you?

There was one person who found the term recovery unhelpful because it reinforced the links with illness. Everyone else thought this was a helpful concept and reflected their experience and their understanding of their health and well-being.

People talked about what recovery meant to them. Often this was in contrast to how they felt when their illness was overwhelming them. Many of the points they raised were very similar to the ways other people have described recovery and the factors that help them recover – for example, the people who took part in the SRN Narrative Research project.

Some people raised their experience of racism and of facing hostility.

“I had never heard the recovery word. Today was the first time I heard it. I like it. It means recovering from mental health problems and from other difficult things that happen in your life.”

“To get better and get on with day to day life.”

“I think about specific things that work for me: flexible support to let me work, study and have a relationship.”

“Feeling that people listen to me.”

“Looking well, not the way my appearance is when I am unwell.”

“Feeling able to cope – with my health and with the attitudes of other people when they are not welcoming.”

“Clear thoughts without being confused.”

“Having people around and feeling comfortable mixing with them”

“Being allowed privacy and time out.”

“Living somewhere that is not racist.”

“Recovery is getting back to where I was before I became ill. But this time, I’ll know how to look after myself, how to stop things overwhelming me.”

“For me, it is about balance – spiritual, emotional, intellectual, physical. I have found that a few staff who work in mental health services in Edinburgh respect what I mean by wellbeing and how important it is to strive for balance in all parts of my life. But most staff are only concerned with one small piece of me. And then they wonder why their treatment is not working. How can it when they do not listen, when they do not help me let my whole being recover and heal?”

How do your friends and family help you in your recovery, or to keep well?

People described how their family and friends helped them. Giving people opportunities to talk was the support that was mentioned most often. People also described practical ways in which family and friends help their recovery.

Some people talked about the ways in which it was difficult for family and friends to support them or offer more support.

“Not focussing on illness but focussing on going forwards and enthusing me to continue to develop and grow. Helping me see all of me and not just the illness.”

“Providing real opportunities rather than the sheltered opportunities which make me feel like a laboratory animal.”

“Being supportive. Being able to talk to them and being understanding. Always being there if I need them.”

“They help out with housework, cook meals sometimes. My brother helps me with business side like bills and money.”

“My wife is the person who keeps me well and makes sure that I look after myself.”

“My Mum told me I was doing certain things which I was not aware of. I tried to act on these, what my mum was telling me about my behaviour was helpful. My Mum guides me as to what is right and wrong. She keeps me on the right track. If my Mum was not there I would be struggling with my life.”

“My whole family support has been very helpful. My Dad gives me hope. My Dad says that every day is not the same and he says do not give up, keep going. It gives me mental support. My Dad got me a business that helps me to build routine in my life.”

“My friends and family care about me and do support me. But they are not a big part of my recovery or keeping well. It is something I have to do myself with help from my doctor and other people who give me good advice and support.”

“My family have their own difficulties. Relatives have been seriously ill and this has been a worry for other members of the family as well as for me.”

“My husband is also under a lot of pressure from work, looking after our family and wider family responsibilities here and back at home. I worry about him and he worries about me. But it is hard to also give each other the extra support.”

“Some of my friends are very supportive. White Scottish friends as well as friends from my community and other ethnic communities in Edinburgh. But other people find it too difficult to accept that I am unwell. Our culture is to always be positive, to always tell other people that everything is going well. Someone who was well and then became mentally ill is too frightening. I get a lot of support through Saheliya, because there we can all be honest with each other.”

What would help your friends or family, or other people you know, keep well?

People talked about what would help their family or other people in their community look after their own mental health and wellbeing.

They also talked about things that would help people understand more about mental ill-health. They saw benefits in people from BM communities knowing more about mental health and wellbeing in terms of their own mental health and to help them understand when a relative or friend became unwell. Some of the

ideas they suggested were also aimed at improving understanding among everyone, including the majority community.

“Enthusiasm and hope, being open to new ideas and having people around to support change and development.”

“Looking after their selves - physical and mental health.”

“Having enough information about their health.”

“Having support, people around to advise them.”

“Having something meaningful to do.”

“My family needs help to keep them going. My mum would appreciate some support as our community’s attitude is very negative towards mentally ill people.”

“Less responsibility. Too many people in our community, and probably other communities as well, take on a lot of responsibility – looking after their family, running a business, keeping in touch with family in Pakistan and spread far across the world. We don’t ask for help. Sometimes we need to say ‘no’ or ‘not just now’ for our own wellbeing. But that is not what we have learned.”

“Realising that anyone can have depression or become unwell in other ways. Not thinking that because someone has coped well all their lives, or looks as if they have coped, that they cannot be ill.”

“Accepting that anyone can become unwell – physically or mentally. It is not a sign of weakness. It isn’t the work of devils. It isn’t anyone’s fault. It is just something that happens.”

“It helped me when Rashpal explained about the medication and why I needed to keep taking it. I had gone on holiday and my family told me that I was cured, I didn’t need to take the pills. I became very unwell again. I ended up back in hospital. But my family were not trying to hurt me. This way of treating illness is different from their way. Families need information about illness and treatment in a way that they can understand, the way Rashpal explained it to me.”

“More information for families about mental illness, in ways that ordinary people understand. I used to think it was just us who didn’t understand.”

“Information for children. Our children were very young when my husband first became ill. They have lived with him being unwell all their lives. No-one has even given us information to help us explain to them what is happening. And now they are at the age when sometimes the other children at school comment when

their dad behaves in an unusual way. They have to explain that he is ill. There doesn't seem to even be any information in English for white children."

"Since I became not well this is having an impact on my children's wellbeing. I am constantly worrying about them."

"I used to get depressed. I did not have anybody who I could turn to. Some relatives have stopped talking to me cause of my son's illness. I take my son to Men in Mind to help him get better. I took my son everywhere because he did not have motivation to go out to his appointments. No social worker was helpful. No one was there to support me." (mother who took part in the interview as a carer)

Other supports

We asked people if there was anything else they think would help people in BME communities living in this area in their recovery from mental health problems

People suggested a range of approaches that would be helpful. They also talked about the messages they would want to give to people in different roles and situations.

Message for people living with mental health problems

"Focus on hope."

"Mix with similar people so you feel you're not alone, socialise."

"Find out what makes you laugh and be happy."

"Live in a nice place. Take responsibility for looking after yourself and keeping safe. Be aware of rough areas at night. Pick the safe areas to live in."

"Getting hope from hearing how other people facilitated their own recovery."

"Linking with organisation for support – like Saheliya."

"Reminding people that Edinburgh is not racist, there are no barriers to services."

"I would remind people that there are many good staff working in services who are welcoming and want to give good support to people from minority communities. So we have to tell them how we want them to support us."

"Remembering that it takes time to recover from an illness – mental illness and from a physical illness. "

“Talk about your experiences. Today I found myself very relaxed and more comfortable, with the confidence to talk, with someone there to listen to my story and this has given me the confidence to share my experiences as a mental health service user.”

Messages for friends and families, or for the wider BME communities

“What would help? – people within our community offering to help when someone is under a lot of pressure, or sharing some of the work.”

“Realising that some young people are not yet ready to take on responsibilities for their family. It can be a lot for a young man in his 20s to have several people relying on him. For some young men, this is fine. But for others, they need more time.”

“More people having information about ways to manage symptoms such as not being able to sleep. Some people know about complementary therapies such as massage and aromatherapy because they are in touch with mental health projects. But lots of women and men from minority communities won't know about these things.”

“The lack of understanding and the stigma make it more difficult for people to recover. For a long time I did not tell anybody that I was suffering from mental illness. The community does not understand mental health problems.”

“My message is don't be afraid of mental illness. Don't deny that it happens in our community. Don't put off asking for help.”

“We all need to spend time with our families and friends. My parents worked very hard when I was young and did not have much time to spend with their children. I didn't get much love and affection from them. I think that may be why I am not confident with people. I try to enjoy looking after my children now as I want them to be happy and confident in the future.”

“An anti-stigma campaign would be useful to change attitudes and increase understanding about mental health.”

Messages for mental health services which provide support

“Staff in services should stop filling in forms and reading from textbooks. Remember that we're real people. Talk to us.”

“Work out if people feel conscious of their race, is this a barrier for them? If so, what can you do to welcome them and help them feel more comfortable?”

“It would help a lot if people have the choice of who helps you, like choosing your CPN or psychiatrist, and not just be assigned to a worker.”

“What helps? Good GPs who can understand you and support you.”

“I have had good support from staff which helped me to recover, especially from an OT and my GP.”

“Good GPs and CPNs.”

“It would help to have practical help to deal with the consequences of medication which are also distressing. For me it has been the weight gain.”

“More people who listen, sympathetic ears.”

“Being able to talk to someone when I am feeling anxious is good. If Rashpal had not been there, I would have struggled. If other hospitals had a post similar to Rashpal’s this would be good. This person in the post would not necessarily have to be Asian, but just someone available who understands the needs of patients.”

“It often feels that white people do not try to understand me. What would help? Better understanding of what life is like in other cultures and other places. People who take time to listen and understand.”

“Remember that medication is not the only solution to keeping well.”

“A more appropriate holistic approach would be useful.”

“It would make a big difference if there were people who take an interest in all of my life. Sometimes staff who work in mental health services seem to have no idea what it is like when you do not have any access to public funds. I was too ill to work. I was surviving on a few pounds a week that I got from my family. I walked to the clinic because I could not afford a bus. Sometimes I wasn’t eating because I couldn’t afford it. But no-one asked about that.”

“This illness can come to anybody. The NHS needs to tell people about illness so they can understand. That will help recovery”

Contribution of wider community resources

“I was given a council property in Edinburgh. It was following a very difficult time in my life and this was the start of moving on. I suffered racial problems. My local Councillor listened to me and helped me. I got a good council house in another area and I was very happy. This helped me recover from my mental illness.”

“Local facilities like Thistle Foundation – gym etc.”

“Once a week I go to a session at a community drop-in centre which is for women. It is something to look forward to.”

“I would like to have a more supportive environment, with more interaction, and resources for BME communities.”

“Help with managing a good diet.”

“Entertainment which meets the needs of BME communities.”

“More information about things like volunteering or activities that give you a chance to making a contribution or learn or just have fun. Too many people in BME communities are spending time on their own. They are not mixing with other people and not making a contribution. Their confidence and skills just waste away. It is not good for their mental health. And it isn't good for anyone else.”

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