CSIP COMMUNITY MENTAL HEALTH RESEARCH REPORT

Inequalities and Cultural Needs in Mental Health Service Provision for
Black and Minority Ethnic communities in Liverpool

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Executive Summary

This project engaged three widely differing community organisations i.e. Asylum Link Merseyside (ALM), Irish Community Care Merseyside (ICCM) and Merseyside Chinese Community Development Association (MCCDA). It tasked them both collectively and individually with working together to identify the difficulties associated with accessing mental health services. It also sought solutions to these difficulties. The project was challenging, time consuming and rewarding. The aims have been realised and are set out briefly in this summary.

This Community Engagement Project (CEP) we undertook was one of forty national projects undertaken in 2007/2008 under the initiative of Delivering Race Equality in Mental Health Care funded by NIMHE and managed and supported by the University of Central Lancashire (UCLAN). The projects, carried out by Service Users themselves, provide detailed needs assessment information to steering groups comprising key local stakeholders. This enables service improvement as part of local delivery plans. The overall aim is to effectively improve the design and delivery of mental health services in accordance with the 12 key areas highlighted in the Delivering Race Equality in Mental Health Care Action Plan (DoH 2005).

Our project looked at the mental health experiences of specific Black & Minority Ethnic (BME) communities living in Liverpool i.e. Asylum Seekers and Refugees, Irish and Irish Travellers and Chinese Elders. It was unique as it involved three different community organisations presenting a collective voice through the research report.

What was obvious at the beginning of the project was how few, if any, of the Service Users in the respective communities had ever been consulted on their experiences of mental health services including access and suggestions for improvement. The experiences of the three groups, with one or two exceptions, were very similar, despite the huge differences in background. This is not to say, however, that it is possible to have a 'one size fits all' approach. In fact the opposite is true.

Another startling fact was that many individuals, who according to the Mental Health Screening Tool PHQ9 score indicated an existing mental health issue,

yet had not sought help. Clearly the needs of these individuals have not been addressed, and many distressed people continue to slip through the net.
This report identifies three main areas for improvement:

1. Provision of Information

Information needs to be universally available, in translated form if required, and suited to the needs of the community accessing it. It needs to be available in a wide variety of places and should describe the services offered and details on how to access them. The information should be tailored to local services in each area.

Proper account needs to be taken of people's need for spoken information. This applies to people who prefer and can assimilate information this way, people who may have literacy difficulties and people for whom English is not their first language. This could be facilitated through face-to-face contact with support workers and also through video in waiting rooms and community spaces. Many people requested information via TV and radio. There is a need for further research into the most effective ways of disseminating information.

The information needs to be widely available at all points in a journey through life from the most casual to the most critical scenarios and encounters i.e. transition, arrival, meeting places, or where people naturally go to access support, advocacy or help.

2. Access through Community Based Support

All the research teams uncovered a need for:
- Quicker and more flexible ways of accessing services
- Making people aware of systems of referral and access to services
- Knowledge of what services are available

The consensus view is that this can best be achieved by health professionals, working in partnership with community organisations. This will ensure immediate access to care, support and advice for Service Users. Advice and guidance can also be provided to staff and volunteers working alongside the health workers.

It is essential that people have immediate access to services at time of need. A system of self-referral needs to be available through a 24/7 Crisis Service - one which is not based merely on access to Accident & Emergency Departments in local acute hospitals.

3. How Care is Explained, Planned, Delivered and Followed Up

People need to have their illness and treatment clearly explained to them. They need to know the possible side effects of medication and be made aware of alternative treatments. Service Users must be integral to the drawing up of care plans and need to fully understand what their care plan means. When all these things happen, unsurprisingly, people's experience and perception of their care is vastly improved.

Health care professionals i.e. psychiatrists, psychologists, GPs, nurses, secretaries and receptionists, need to develop a much better understanding of the specific cultural needs and experiences of BME communities they provide services to. There are no shortcuts and all health professionals must be prepared to take more time to understand, empathise and work competently with BME communities.

Mental Health Trusts and Service Providers need to embed quality cultural awareness, sensitivity and competence training as part of both their staff induction and ongoing professional development programmes. The impact of comprehensive quality training cannot be over emphasised.

This research project has been an adventure into the unknown. This applies not only to the researchers from the three community organisations - consider how people from Kampala, Cork and Kowloon, all sit down together to work out the common questions to be asked of their communities - but also for the managers, staff and volunteers who have hitherto concentrated on their own communities.

The partnership work across the communities has built friendships and developed understanding. This could be mirrored in the way our society meets the needs of BME communities. It has also been very hard work. This project would not have been undertaken if there had not been a screaming imperative for change in the way mental health services are delivered to take account of the needs of vulnerable groups or individuals who are voiceless within our society. Given the day-to-day requirements of serving their communities, the effort made by the organisations to complete the report has been extraordinary.

The recommendations made by the communities have Equal Opportunities and Empowerment at their heart. For us this does not mean treating all people the same, but addressing differences and providing individuals with appropriate support to allow them equal access to the services available to the rest of society.

What has become clear, as the research has progressed is that we are not covering new ground. The research has highlighted that the Black and Minority Ethnic communities involved want to see actions from consultations with positive outcomes. There comes a point where it is no longer appropriate to ask questions of people, without some form of concrete action taking place. We have long since reached that point.

Summary of Research Background and Findings

The Focus of this particular report

The focus of this report on the Community Engagement Programme is the experiences of Asylum Seekers and Refugees, Irish and Irish Travellers and Chinese Elders. The objective of this work is to improve the quality of access, experience and outcomes for the above communities accessing mental health services.

Through the project teams experience of working with our communities we have gained understanding of and gathered information on their needs. We have also highlighted the skills, qualities and resources necessary to our individual organisations in order to deliver services that are culturally appropriate and accessible to the diverse groups.

Aims and Objectives of the work

Our research set out to examine the extent to which the issues identified in the 'Delivering Race Equality in Mental Health Care' action plan (Department of Health 2005), had relevance for BME communities in Liverpool and if any concerns were specific or different. Our intention was to examine these by collecting data from BME communities to ascertain:

- ➢ Access to mental health services in Liverpool

- ➢ Attitudes to mental health services in Liverpool

- ➢ Level of satisfaction with mental health services

- ➢ Experience of the range of therapies, support and treatment available in Liverpool

Project Start up and Researcher background

The 14 researchers represented three groups within the BME communities and were recruited from within those communities. Their cultural background fell into one of the following experiences:

- Born or came to Liverpool with parents or family seeking new opportunities
- Came as adults, from home country, seeking refuge from war, conflict, or persecution
- Came as adults with husbands working in professional occupations in the UK, or for further education

The Community Research Group met regularly in the summer of 2007. We made several trips, as a group, travelling together to the University of Central Lancashire (UCLAN) and also to training in Wigan. We attended workshops, networking events with other research groups, group learning, training and development sessions with the researchers eventually attaining research qualifications. At the start, the researchers came together to agree the research focus, develop questions and agree a format for gathering and recording data. Later, the data we collected from the research was analysed and shared, to arrive at our recommendations for promoting change. We learned the procedures and protocols of academic research during the workshops.

Data Sample

Questionnaires were completed by 104 members of the BME communities aged 18 – 97. There were (47) male and (57) female. Apart from the Irish or Irish Travellers, only one respondent had English as their first language. All Irish or Irish Traveller participants had a previous known history of mental illness. Asylum Seekers and Chinese participants did not necessarily have a previous recorded history of mental illness.

The interviews were carried out with 33 Irish or Irish Travellers, 33 elderly Chinese people and 38 Asylum Seekers and Refugees, from a very diverse set of backgrounds. Focus groups were also conducted by ICCM and MCCDA. People's ages ranged from 18 to 97 and participants came from 29 different language or dialect groups. Within the religions, Christianity predominated, however Islam, Buddhism, Taoism, Ancestor Worship and Paganism were all present.

Key Findings

GP Services
The research results indicate that GPs are the first point of contact with mental health services. The rapid allocation of a GP is therefore crucial.

GP's and primary care staff do not always have up-to-date knowledge on the impact of stigma and discrimination around mental health issues in BME communities. Knowledge of culturally appropriate services in their area is often lacking making appropriate referrals for support and treatment problematic.

It was also found that persistent physical ailments were not always identified as being linked to mental illness.

Delays
There are considerable delays between being referred by the GP and actually seeing a mental health specialist.

Feelings of shame and stigma

Shame, cultural differences and stigma play a major part in the way BME communities view mental illness. Specific stigma around immigration status, language barriers, fear and cultural differences, were the greatest barriers to the Asylum Seeking and elderly Chinese communities. With both the Irish and Irish Traveller population the quality of the services available, difficulty of access to them and the manner in which they were treated on both a social and clinical level were problematic.

The research suggests that lack of empowerment and knowledge perpetuate negative attitudes towards mental illness, and its identity as a 'taboo' or 'unmentionable' subject.

Lack of knowledge

Few participants had knowledge of mental health services or how to access them.

Broader issues

Separation, employment and accommodation issues, poverty, status and threats of deportation all contributed to feelings of being anxious, depressed, isolated and lonely.

These are a selection of comments from research participants:

Memories of Experiences

'When I was 16 I went to my GP. He put me on anti-depressants. I did not go back. He did not seem interested and was not helpful. I did not know that I was depressed. I had no energy, and I did not know that he prescribed me anti-depressants. I took them for 28 days and the feeling eventually went'

'I tried to kill myself – coping with a sick mother and brother – running to meetings about the site and incomers – going to court against the council.

'No one had time to listen to my problems in the hospital. The only ones who got attention were the ones who were on close observation or who were very disruptive. There was one really nice nurse who did listen but she was generally too tied up with the hectic ward life to have time to listen to the quieter patients. I never saw the consultant the whole time I was there'

'I was brought into the Royal later as an emergency, they decided because of my strange presentation (disordered balance and speech due to epilepsy and Acquired Brain Damage) that my problem was solely drink related. They had security escort me out of the hospital at 10 past midnight with my injured face only half treated and without any money to get back to the hostel.'

'I had a bad experience, been 5/6 times to A & E (suicide attempts) they gave me loads of leaflets, but I cannot read or write. I was referred to a GP, seen as an alcoholic'

'Talking, talking, and more talking. No help at all, seeing different people all the time and explaining over and over again'.

'…… as an outpatient, during a period of two years I saw 6 different locums. One of these sent me back out on to the streets in a suicidal state. For the past couple of years I've been lucky enough to have an excellent consultant.'

'Did not see stress as a mental health problem'

'Fear of others, and cannot speak English'

'Fear of possession by evil spirits'

'Belief in alternative medicine'

'Being judged by my past drug history'

'Had a bad experience in the past - I was afraid of looking for professional help'

'Stigma of being an Asylum Seeker'

'Thought that I had asked for so much, I couldn't ask for anymore'

'Doctors didn't understand me when I told him I was anxious, thought it was normal, almost committed suicide upon receiving my refusal letter from Home office'

'I was too upset to talk about anything'

'Did not know how to access GP, NHS and statutory services'

Expressed Wishes

'Information of routes into mental health services'

'Have my illness explained to me'

'To see the same person each time as they already know my problem'

'Side effects of medication explained'

'Proper care planning'

'24 hour mental health crisis service'

'Self referral when help is urgently needed'

'Interpreters who speak a range of Chinese dialects'

'To advertise services on TV and radio'

'Less time waiting for appointments'

Key Recommendations

- Local Commissioners to resource the development of appropriate and responsive services.

- Well publicised easy to access mental health services.

- Comprehensive training for people working in community organisations regarding services available and the access route to those services.

- Ongoing comprehensive training for all health professionals involving all aspects of cultural awareness, sensitivity and competence.

- Partnership work between professionals working in mental health services and community organisations working with Service Users, to deliver appropriate mental health services to minority communities.

- Information that is universally available in easily understood written, spoken and translated form.

- Community counsellors or support workers, who are easily accessible, culturally sensitive and based in the community.

- Services need to recognise the individuality of each Service User, whilst acknowledging the possible impact of their ethnic history and experience. Treatment needs to acknowledge this individuality and be tailored accordingly.

- Partnership work with Service Users to design and develop appropriate Mental Health Services.

- Proper engagement and consultation with Service Users in the shaping and delivery of their care plans and treatment.

- Urgent provision of appropriate treatment for those with Dual Diagnosis.

- An embedding of the Recovery Model into all treatment.

- A good, effective Homeless Outreach Service.

- The development of a Mental Health directory, listing all culturally appropriate services in Liverpool for BME men and women, including community organisations able to offer support. This can be distributed to all Mental Health service providers and voluntary organisations.

- Care packages designed to meet the unique needs of the individual offering a range of treatments and support, which are socially, culturally and spiritually appropriate.

- Health care professionals based within community organisations.

- Mental Health workers with a greater awareness, understanding and sensitivity towards BME cultures.

- Support to grow counsellors from BME communities.

- Services that listen and understand

The recommendations reflect the commonality across the 3 groups. One of the main differences however between the 3 groups was the rapid transit of Asylum Seekers and the need for better reception facilities. Homelessness was not an issue for the elderly Chinese community however this had a significant impact on the Irish community and Asylum Seeking groups.

The priorities for each group are indicated by top responses to question 2:1

What makes you feel happy?

Irish and Irish Travellers   Feeling Safe

Asylum seekers and Refugees   Immigration Status

Elderly Chinese   Family and Friends

Conclusion

This report highlights the lived experiences of Asylum Seekers and Refugees, Chinese Elders and the Irish and Irish Traveller communities in Liverpool in relation to mental health and access to services. It is not a report purely for academic reference - too many of these already exist. The time has come for real committed action. It is absolutely imperative that **all local stakeholders** make use of this report. Consideration needs to be given to the findings that have emerged to address the urgent mental health and well being needs of Liverpool's Black and Minority Ethnic communities.

Our report recommendations are for the urgent attention and the shared responsibility of:

- Commissioners of Mental Health Services in Liverpool
- Liverpool Service Providers across both statutory, voluntary and community sectors
- All Stakeholders