

Northumberland Tyne and Wear



Making it better
involving black and minority ethnic
mental health service
users and carers

Report of two events

July 2008

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Introduction

Two events were held on 27 October 2007 and 7 February 2008 to look at issues and concerns around the involvement of BME service users and carers in the provision, design and commissioning of mental health and well-being services across Northumberland and Tyne and Wear.

The events were organised by the Northumberland Tyne and Wear Mental Health Service User & Carer Network with the Health and Race Equality Forum (HAREF), supported and funded by the Delivering Race Equality in Mental Health Programme.

The Network is keen to involve more BME service users and carers in its work and activities and was looking for practical support and ideas.

The events involved a wide range of individuals, user groups along with service providers. Both events were designed around workshops to give people the maximum chance to raise their concerns and issues and to say what they would like to see happen in the future.

This is a write-up of what was said at the two events. The Network will be sharing this information and thinking about how it can use the ideas and issues raised to further its work involving BME service users and carers.

The Northumberland Tyne and Wear Mental Health Service User & Carer Network

We operate in the area of mental health service user and carer involvement. That is to say, we are all (staff included) people who use mental health (MH) services, or care for those using mental health services, and we work to ensure that the voices of the service user and carer are heard in all the decision-making bodies that affect mental health.

The **NTWSU&C network** encompasses just about all of the (adult) MH user and carer groups in the area, from Launchpad in Newcastle to User Voice in Northumberland, Gateshead MH user forum/Pathways, UCAN in North Tyneside, Headlight in Sunderland and dozens more. This allows for wider-scale working, pooling of resources where applicable, and for service users to have a far greater impact at the higher levels of mental health services. It also gives a far broader base for embarking upon research, for better peer support, and has been instrumental in the formation of a regional (North East wide) User and Carer network, which is embryonic but with great potential.

In order to accurately represent the great breadth and depth of mental health service user and carer opinion, we run focus groups, do a lot of outreach work, work with in-patients, produce guides to day and other MH services, and we constantly seek out the views of all MH users and carers, including BME groups, MH users/carers with sensory impairments, those with challenging behaviours, those neglected by services, as well as the more obvious or vocal users and carers: in short, we hope to cover everybody.

We also campaign against the stigma that all too often is attached to having a mental health problem, strive to improve the lot of the service user and carer, to inform the training of MH professionals, and to dispel myths that the public may believe regarding mental health issues.

This also entails getting carers and service users involved in research, from simple participation right through to user/carer-originated, user/carer-focused, user/carer-delivered research. People who use, or those who care for those who use, services are 'experts by experience', and our knowledge and insight is invaluable for any attempt to improve the mental health system.

We try to put across service user and carer views, and indeed deliver training, to bodies as diverse as the Strategic Health Authority, Primary Care Trusts, the Northumberland, Tyne and Wear NHS Trust (NTW), the local authorities, social service departments, the police, voluntary organisations, charities, and MPs, to name just a few. The user and carer voice needs to be heard in strategic policy and clinical guidelines too, so we seek to influence both health and social care, from NICE guidelines to Department of Work and Pension protocols.

If you want to know more or get involved in the Network please contact:

South of the Tyne - Mish Lorraine

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North of Tyne - Alisdair Cameron

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The Health and Race Equality Forum (HAREF)

The Health and Race Equality Forum:

- Is a network of over 100 practitioners in the community, voluntary and statutory sectors in Newcastle upon Tyne.
- Identifies gaps in service provision and works in partnership to address these.
- Promotes easy access to information about services, free from discrimination, to enable people in diverse communities to make informed choices about health.
- Supports communities to share ideas about how they want to be involved in local service developments.
- Develops equality and diversity training.
- Works with professionals to increase understanding of barriers to services, based on real experiences.

The forum provides a place where we can:

- Listen to and learn from each other.
- Celebrate and share good practice.
- Reflect on our own cultural experiences and ways of expressing health needs, as well as learn about backgrounds other than our own.

For more information and to get involved please contact Ann McNulty at HAREF

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1. What do we mean by involvement? Why is involvement important?

1. That people have an equal, meaningful and respected part in all and every level, of the decision making process.
2. It will lead to patient centred services that people want and will use.
3. Consultation from the start, when services are first being considered and designed.
4. Being involved in the decision making about service provision.
5. Making a real concrete difference.
6. It should be a collaborative person centred process, recognising that people will want to take part in different levels of involvement.

2. How do people want to be involved?

1. We must have mutual respect, everyone has their own expertise.
2. Keep people informed and acknowledge their contributions.
3. Provide practical support so that people can take part, upfront payments for travel, personal assistance, carer costs, communication support.
4. Provide peer or worker support for service users and carers who are involved, before, during and after meetings.
5. Encourage and support pre-meetings and de-briefings.
6. Information must be understandable, provided in plenty of time and in appropriate formats and languages.
7. Offer criticism positively and be willing to learn from the negative.

3. What needs to be done to improve involvement?

3a. More support for BME work and issues

1. The Mental Health Service User & Carer Network would like to work more closely with the BME community development workers and other workers in the Delivering Race Equality Programme.
2. Existing mental health user and carer networks need more representation from, and involvement with, BME groups.
3. More linking between the statutory organisations and voluntary groups.
4. How do we work effectively together, especially where groups are doing similar work?
5. Need involvement in the new Local involvement Networks, start to join things up.
6. Health and social care providers have statutory duties to involve and engage when changing and/or developing services – we need this ability to influence commissioners.
7. We need more support and funding for the work of voluntary and community groups, which is consistent and provided long term.

3b. Improve information

1. Provide information on the preventative, community based, services that are already out there.
2. Need clear information on the care pathways, who does what when and where.
3. There are still difficulties in getting translated information in some languages and in arranging interpreters for appointments etc.
4. General concern about lack of appropriate information on services and support and the problems in accessing the information that is there.
5. Information does not get out to BME groups and communities.
6. Information is not always culturally relevant.
7. Update the Newcastle BME Service Directory

3c. Raise awareness and understanding

1. More work needs to be done in raising awareness in primary care of BME mental health issues.
2. Staff working in mental health need better awareness of culture and faith.

3d. Tackle stigma

1. Think about the labels and terms we use, is 'service user' appropriate?
2. More work is needed to address the stigma around mental health, culturally and within communities and families.

3e. Tackle inequalities in provision

1. Look at and map BME service provision across the area – is there equal access to services, are there enough services?

3f. Improve access to services

1. Look at referrals into community mental health teams by people and organisations other than GPs.
2. Need a 'one-stop shop' approach.
3. We are not good at addressing multiple needs.
4. Services, policies and procedures have to be culturally relevant, sensitive and appropriate.
5. More emphasis on encouraging mental well-being.
6. Need to encourage and provide choice about care.
7. Be willing to explore and support 'non-western' approaches to supporting and healing.
8. Where appropriate, adopt a family approach.
9. People want less drugs and more opportunities to talk to people they can trust.

4. What next?

1. We need to build a BME mental health network, properly financed and resourced with regular meetings.
2. The network must have the trust of local BME communities.
3. Think about what is needed in each locality as well as Trust wide.
4. We must share information and resources.
5. Develop a list of named contacts.
6. Set up feedback mechanisms.
7. Provide training and mentoring.
8. Talk to health and social care commissioners about how and when we want and need to be involved.
9. Explore more ways of involving people, not only events and meetings.
10. Identify the support, organisations and structures, we need to enable full BME service user and carer involvement.
11. Publicise what is happening more widely.

and people would like another event which ...

12. Is held in a bigger and cooler venue away from the centre of Newcastle.
13. Allows people from the same locality to talk more about their local concerns (or we have more local meetings to take work forward).
14. Involves senior decision makers who could respond to issues raised and say what is being done or what will be done.
15. Involves more people from BME communities and groups.
16. Explores how BME communities view mental health.
17. Looks at examples, achievements and problems from work around BME mental health, what links have been made and what service are being provided and/or planned.

18. Provides an update as to what is happening around Delivering Race Equality and what will happen when the Focussed Implementation Site closes.
19. Provides action points we can work on, including how this work will continue.

Appendix 1

What is already happening – what links are there?

Gateshead

- Mental Health User Forum – promoting service user involvement in services.
- Crossroads Caring for Carers – mental health carer involvement and support workers
- DRE Community Development Workers in BME Community Tyneside Women’s Health – BME Community Development Workers.
- MIND in Gateshead.
- North East Refugee Service.
- NTW Mental Health Trust.
- Community Based Services – Refugee Team.
- Pathways.
- Citizens Advice Bureau.
- Churches.
- Gateshead College.
- Diversity Forum.
- Angelou Centre.
- Gateshead Carers.
- Police.
- Gateshead Housing Company.
- Schools.
- Students.

Newcastle

- Newcastle Primary Care Trust – Barbara Quinn,
- Carer Support, Carer Centre and Mel Cartlidge, Community Development Worker.
- Mental Health Matters
- Local Strategic Partnership.
- Newcastle Community Empowerment Network.
- Unaccompanied Minors Team.
- Children and Adolescent Mental Health Services.
- Health and Race Equality Forum.
- Newcastle Medical School.

- Launchpad.
- ACANE.
- Arts for Health involvement.
- Freedom Think Tank.
- Medical students.
- Dementia Care Partnership.
- Doctors of BME background.
- Community Spiritual Leaders.
- Advocacy for BME communities in Newcastle.

Northumberland

- Angelou Centre.
- Faith Groups.
- Northumbria University – Dan Hamilton, Student Mental Health Nurse.
- Primary Care Mental Health Workers/counsellors.
- Newcastle University
- NTW user/carer involvement – Helen Chandler.
- Day Activities – Kay Enterprise Avenues.
- Housing
- Employment – Shaw Trust, Job Centre Plus, African Women's Group.
- Morpeth – Working Well in Northumberland, Healthy Living Centres, Women's Health Advice Centre.
- Launchpad
- CSIP – Paul Johnson.
- NTW user/carer network.
- Voluntary and Statutory Services.
- All mental health work with services users and carers.

South Tyneside

- Mental Health in South Tyneside.
- South Tyneside Advocacy Consensus.
- South of Tyne and Wear Service User Network.
- South of Tyne and Wear Mental Health Carers Liaison Group.
- Mental Health North East.

Sunderland

- DRE Mental Health Team
- Sunderland Carers Centre – Mental Health Carer Support workers.
- Headlight.
- BME Network.
- Sunderland Partnership.
- MIND.
- WWIN.
- Asylum Seekers and Refugee.
- Sangini.
- Washington Citizens Advice Bureau.
- Art Studio.
- New Beginnings.
- WASP.
- Sunderland University.
- CVS.
- Voluntary and Community Groups.
- GP's.

Appendix 2

How to improve services

1. Develop the use of expert patients in mental health.
2. More training for volunteers and advocates from BME communities.
3. Make professionals more aware of different cultures.
4. Consider a range of therapies, head massage, talking to people. Provide the negatives and side-effects of medication.
5. Adopt a family approach – in Britain the focus is on the patient, in other countries the family is often included in the therapy.
6. However, sometimes families are part of the problem. Make sure that services use a reputable translator, someone who is not conspiring with the family.
7. Organisations need to work together and refer people to each other.
8. Consultations should be in relevant languages and translations paid for.
9. GPs need to work much more in collaboration with other agencies such as advocacy centres, community development workers and service user forums.
10. Employ bi-lingual staff.
11. Make sure that examples of good practice are shared widely and that staff are kept up to date and trained.
12. Psychiatry needs to work with pastors and imams e.g. a man in hospital seeing pastor, afraid to be killed, pastor prayed then passed to psychiatrist (“can’t harm you now”).
13. It needs to be clear that this is a confidential system.
14. Use community groups to explain Mental Health and what help is available, make people aware through friends and family
15. Develop a map of services so that everyone can understand who fits where!
16. People are individuals and we should not be developing one size fits all BME services. Make services personal and person centred.