'Deciding together' group discussions facilitated by HAREF and supported by bilingual workers, January 2015

Participants

24 people, 22 women and 2 men, took part in three separate group discussions: 8 in the first group, 6 in the second, and 10 in the third.

5 participants were in the 26-35 age range; 7 in the 36-45 range; 1 in the 46-55 range; 9 in the 56-65 range and 2 in the 66-75 range.

4 people identified themselves as a carer.

10 people described themselves as Chinese; 6 as central European (from Czech Republic and Slovakia); 1 as Black African; 1 as Indian; and 6 as Pakistani.

The 14 participants who gave their postcode all live in the NE4 area of Newcastle.

Themes from group discussions

1. Being equipped to know when and how to contact services and use them effectively

Feedback across the three group discussions was that:

- people want to raise their awareness of the symptoms of mental ill health - "so that we know what to look out for if someone is becoming ill. It would be very helpful if there was some training for community members about mental illness and how to respond, with a refresher session every year or so."

- people need to know when and how to ask for help in advance of services being needed. The importance of people having information before the need for service provision so that they, or someone close to them, knows who to get in touch with, was illustrated by a woman in one of the groups who has experienced suicidal feelings - "Sometimes I still hear voices saying negative things and when those thoughts come I feel I want to end it. You need to know in advance what to do when you feel like that. You never know when you're going to feel worse though some things can trigger it, like domestic violence and things to do with immigration status". Another participant talked about being in the centre of Newcastle with a friend and hearing voices - "It was like a blare in my head. My friend brought me straight back from town and took me to (community organisation that both of them use) and they made an emergency appointment with my GP".

- access needs to be as easy as possible at the point of need.

2. Breaking down barriers

2a. People who are parents

People who are parenting without an extended family network, for example people who have arrived in the UK seeking asylum, can struggle to find information and support:

- "It's very hard when you have no family around you and you don't know where to go and what to do".

Participants suggested that it is invaluable to be linked with community organisations, with whom they can stay in touch and who can signpost to appropriate support.

Several participants highlighted the importance of professionals explaining ways of managing medication to avoid side effects that get in the way of day to day life as a parent:

- "I am on my own with my children and it's difficult to get going in the morning and I sometimes feel dizzy. I feel tired and more down. I go to bed at 5 or 6pm and take my tablets all at once to be able to get up to take the children to school."

Similarly there was reference to the importance of professionals outlining lines of responsibility eg duty of care to dependent children of people experiencing mental ill health, and ways of working with the person who is ill to explore best outcomes, to build trust and avoid situations in which people are frightened to share how they are feeling:

- "My children are my life. Some doctors are scaring me away because when I explain what I'm going through they say "How can you cope?". I am worried that they will take my children away. Fear gets in the way of me saying how I feel."

2b. People who are in a minority within service settings

It is important that service providers are welcoming and support interaction with others as appropriate:

- "Some people find it quite daunting to be in hospital and to be the only one not from the majority population. If you put someone in that situation they often feel isolated and worse than before. The staff really supported me to start to interact with other people in the place and that helped."

2c. People with a first language other than English

It is important that service providers sensitively check out whether people need support to negotiate services, and if yes, which language/dialect:

- "Sometimes you might really need to see a doctor and If you can't explain things it's difficult."

- "Services need to think about language support. We really appreciate good interpreting."

- "They need to properly match people in terms of their language needs. Sometimes a mainland Chinese interpreter will be booked, even though the majority of people in the Newcastle Chinese

community speak Cantonese or Hakka. And although most people who speak Hakka can speak Cantonese it's not necessarily the same the other way round. Services need to double check."

2d. People affected by the stigma of mental illness

Stigma was mentioned in all of the group discussions as a potential barrier to using services. While this is a barrier affecting people across both majority and minority ethnic communities, the combination of stigma with some or all of the barriers highlighted above can complicate access to, and effective use of, services:

- "Stigma is very strong within the community and people don't want others to know they have a mental illness. This stops people getting help when they need it."

3. Managing distance between home and service provision

22 of 24 participants expressed the view that specialist services should be provided somewhere in the city (Newcastle), because of the importance of not becoming isolated from support networks, for example:

- "If it's in Newcastle it would be easier for family to visit."

- "If it's in Newcastle that's manageable because it's not too big a city."

Two participants suggested that urgency of need for care would outweigh travel distance:

- "If it is necessary people will be happy to travel."

- "It wouldn't matter how far if people needed help desperately."

However, while a small number of people across the three groups said that they have a car, and some said that they can afford to use public transport, a third (8) of participants highlighted practical issues related to travelling long distances, namely cost, for people with low income, and time, particularly for people with family responsibilities and no private form of transport:

- "It can be difficult to get to towns outside of Newcastle by bus. If you miss the bus you have to wait another hour."

- "The bus fare is expensive and some people would not be able to afford to visit."

4. Services linking with voluntary and community sector organisations

In all of the group discussions there was reference to the importance of what one person called "the invisible network" of support provided by voluntary and community sector organisations. This network provides access to information about symptoms of mental ill health and who to contact if needed:

- "We feel comfortable in the women's group and it's easier to take in information."

Several examples were given of invaluable support provided by workers in community and voluntary sector organisations, and also of positive and productive liaison/working links between them and Newcastle specialist mental health teams:

- "A worker from (local community development organisation) came with me and that was very important to actually get me there."

- "I was sectioned and the worker from (community organisation) visited me by public transport and kept support going by telephone in between visits."

However a bilingual worker supporting one of the group discussions commented that recognition of the value of working together needs to be embedded within the culture of statutory sector organisations providing specialist mental health services, rather than reliance on the initiative and commitment of one or two individual workers.

5. Experience of service provision

Things that people across the three group discussions said that they particularly value are:

- professionals having a friendly, respectful, non-judgmental approach

- professionals' capacity to be patient

- a caring approach

- good communication skills

- evidence of good quality training

- professionals understanding dynamics of domestic violence within different cultural contexts, and the impact on women's mental health

- a clean, bright environment

- food that meets the needs of a range of people

- support for people across the range of faith positions eg to pray while in-patient.

Feedback about specialist mental health professionals was generally very positive as illustrated below:

- "The psychiatrist really listened and gave me a plan, a structure, and a review time."

- "I really like how the doctor talks to me and how she tries to understand me."

- "They put things in a way that you can understand so you can fall back on that if you have any problem."

- "I had excellent care when I was an inpatient. The staff were always checking on me in a way that felt caring. and the occupational therapy group work was very good."

- "It feels as though staff are well prepared now to support people to practice their faith while they are in-patient."