



Supporting people with epilepsy

**EPILEPSY CONNECTIONS  
MULTICULTURAL PROJECT**

**Report on Dissemination Day**

**Held on 31 October 2007**

**Epilepsy Connections, 100 Wellington Street, Glasgow, G2 6DH**

**A Brief Overview of the Event**

**Background**

Epilepsy Connections provides information and support to people with epilepsy, their families and friends and those with whom they live and work. In 2003, Epilepsy Connections set up the Multicultural Project, the first in Scotland to identify and address the specific information and support needs of BME people with epilepsy.

The need for the Multicultural Project arose as it was recognised that the service user profile of Epilepsy Connections did not reflect the increasingly diverse population of Glasgow. This coupled with the fact that Epilepsy Connections has as one of its aims to provide services that are fair and accessible to all regardless of race, religion or ethnic group, meant that Epilepsy Connections had a legal obligation to proactively provide culturally-sensitive services and information to BME people affected by epilepsy.

The Multicultural Project provides bi-lingual culturally-sensitive information and support to people affected by epilepsy in ethnic minority communities. Members of ethnic minority communities can discuss their circumstances in confidence with staff who understand Urdu, Punjabi and Cantonese and have an in-depth understanding of other cultural perspectives. Support can also be provided at epilepsy-related hospital appointments to ensure that communication problems and language barriers do not stop people with epilepsy fully understanding their condition and treatment. The Multicultural Project also provides special interest groups e.g. BME carers groups to offer mutual support and to allow for the exchange of ideas and sharing of knowledge and experience of epilepsy.

In 2005, Project Worker Farhat Khan carried out a small-scale research project into beliefs about and attitudes towards epilepsy in BME communities and produced a report titled 'Epilepsy, Culture and Religion: Attitudes in Black

Minority Ethnic Groups in Glasgow', which was widely circulated and formed the basis for the agenda of the recent BME dissemination day held by Epilepsy connections, held in order to share the findings of the report and its impact on engaging with BME communities.

The BME dissemination event coincided with the timing of the recent NHS Showcase event organised by the National Resource Centre for Ethnic Minority Health(NRCEMH). This event focused on race equality work carried out in Scotland by the NHS and their partner agencies in the 5 years since the launch of the Fair for All policy, which placed an obligation on statutory organisations and voluntary organisations to proactively provide services to clients in ways that are culturally appropriate.

This report serves to provide a brief outline of the dissemination day.

### **Purpose of the BME Dissemination Day:**

- To raise awareness about the services that Epilepsy Connections and the 'Multicultural Project' offers
- To briefly review the key findings from the 2005 report
- To share our experiences, and that of our service users, of putting the report's recommendations into practice
- To look at the barriers that still prevent BME people from accessing Epilepsy Connections service provision
- To look at how we might work with other agencies working with BME communities to raise awareness of epilepsy and of our services and to develop models of successful practice in engaging with BME communities in relation to health.
- To share information about the needs of BME people when accessing health related information and the barriers that they face so that other health professionals have more knowledge on how to engage with BME communities accurately.

### **Who attended the event:**

83 individuals were invited to attend the event including MSPS on the Epilepsy cross party group, local councillors, Epilepsy Specialist Nurses, Epilepsy Project Workers, health professionals, staff from voluntary organisations and representatives from BME based social and health organisations and BME service users.

### **The above groups/individuals were invited as:**

- They were thought to have a perceived interest in epilepsy and a commitment to tackling health inequalities
- It would provide policy makers and service providers with useful information and insights about the barriers faced by BME community members in accessing support in relation to health issues.
- It would provide a networking and learning opportunity.

- It would allow service users to shape the way future services are delivered, to ensure that it takes accounts of their specific needs.

On the day 11 people attended including Epilepsy Specialist Nurses, Psychologists, Epilepsy specialists, representatives from BME organisations and one Epilepsy Connections BME service user.

### **Impact of the report 'Epilepsy, Culture and Religion'**

The report looked at the knowledge and experiences of epilepsy amongst BME groups in Glasgow and it also gave BME people an opportunity to suggest ways in which they believe information and support could be provided to BME people with epilepsy and their families, in a culturally acceptable way.

### **Methodology used in the study**

- 'Soft' research study with 42 questionnaires and 4 focus groups.
- The ethnicity of the groups involved in the study were; Chinese, Pakistani, Indian, Malaysian and Afghanistani.(For detailed statistics refer to BME Report 2005).

### **Knowledge and experiences of epilepsy**

Amongst the BME communities knowledge of epilepsy was high, even if family members or friends had not suffered from the condition. However a high level knowledge of epilepsy amongst BME groups, did not preclude negative experiences of living with a condition that was still surrounded by myth and stigma.

Many people believed that epilepsy is a health condition not like any other and it greatly affects your ability to lead a normal life, ie being able to get married, have a fulfilling family life or be active in the labour market or achieve a successful level of education.(For more information refer to BME Report 2005).

Individuals who took part in the study were also asked to give suggestions about ways that services and information could be provided in a culturally-appropriate way to BME people with epilepsy and their families, the suggestions are detailed below.

### **Suggestions for Culturally Sensitive Services from Research Participants**

- Epilepsy Awareness raising amongst BME organisations and BME communities in general
- Support within own community to reduce isolation
- Shopping, games, taken to church/mosque, learning the Quran
- Bi-lingual information leaflets in easily accessible places
- Culturally-sensitive befriending type activities

- Specific activity groups to reduce isolation
- Religious/cultural activities for people with epilepsy to learn about their own ideals and values
- Some said women doctors for Muslim girls

### **Actions taken by Epilepsy Connections as a result of the report:**

- Culturally appropriate and bi-lingual Epilepsy Awareness sessions were delivered to 20 BME disability/social based organisation in the Glasgow area.
- Development of bi-lingual literature and publicity and distribution to GP surgeries, hospitals, pharmacies, community-based BME organisations and places of worship.
- Bi-lingual information was placed in local media to ensure services are more accessible to BME people.
- Presentations delivered to social work/health professionals in areas with a high BME population to encourage future referrals
- Provided cultural awareness training to Epilepsy Connections staff to ensure frontline services are provided in a culturally-responsive way.
- Multicultural Epilepsy Awareness Workshop delivered to BME people with epilepsy and their carers to aid correct understanding of the condition and management of the condition.
- Development of Befriending service to make it more culturally appropriate in terms of volunteer training and through the recruitment of bi-lingual BME volunteers to the organisation.
- Introduced culturally-sensitive Women's Epilepsy Information Groups and Glass Painting sessions for BME individuals and carers affected by epilepsy, in order to offer them a mutual support network in which they could share and exchange their knowledge and experience of epilepsy.
- An Outreach Drop In Information Room, was piloted in the area of Glasgow, with the highest BME population, to make information more accessible to these groups.

### **Summary of Achievements Made**

- Increase in the uptake of services by BME people.
- Development and dissemination of bi-lingual literature promoting the Multicultural Project
- Befriending service is more culturally responsive to BME client needs
- More awareness of epilepsy and safe management of seizures amongst BME communities
- More awareness amongst GP surgeries, social work, mainstream service providers and BME organisations about range of EC services provided.

- Epilepsy Connections staff/workers feel trained and supported in consulting and engaging with a range of ethnic minority clients and staff, user groups and representative bodies etc.
- More culturally sensitive services have been introduced.

**Barriers that still exist in integrating the BME communities fully into service provision**

- Despite awareness of services most BME people affected by epilepsy still choose to refuse or delay accessing help due to wanting to conceal ill health and wanting to appear as 'normal' as possible in the community.
- Practical factors, travelling limited time due to high levels of family responsibilities in BME culture.
- Confidentiality and pride, as people do not want to ask for help due to the fear of rejection from the community if they find out about the condition.
- Language problems and cultural differences between service user and the service provider.
- Lack of inter-agency referrals from other community-based health, disability/social organisations and GP surgeries, despite awareness being raised about range of services offered.

**DISCUSSION**

As part of the Dissemination day participative workshops were held to look at ways of working with other agencies and developing models of successful practice in engaging with BME communities.

The questions that were discussed during the Workshop session and the responses that were received are detailed below;

**1. What do you think are the main needs of people from BME communities when accessing health-related information and support services?**

- Language appropriate – more readable, less formal
- Culturally 'sensitive' service (being able to speak to someone from the same culture)
- Confidentiality and issues of trust
- Reassurance
- Rapport building
- More local services
- More advertising of services
- Support – to use services that exist

- Advocates that can support BME individuals to access services
- 2. What do you think are the main barriers preventing BME community members from accessing health-related information & support services?**
- Trust
  - Cultural beliefs of older generation
  - Lack of education regarding epilepsy
  - Lack of information about services
  - Lack of awareness between existing service providers to refer clients to each other
  - Protective family members resist access to support or advocacy
  - Lack of social integration in general by BME groups
- 3. What issues do organisations face in engaging with BME communities?**
- Build up of rapport with clients
  - Knowing how to correctly engage with BME people, how to get them in for treatments, how to get people to go to GP's etc
- 4. Within this room, are there potential partnerships or ways of working that might enhance uptake of health-related information & support services?**
- Links via distribution of leaflets/posters
  - Networking between health professionals referring on to other organisation
  - Holding events similar to this one to create awareness of specific services provided for BME people.

As a result of the feedback received from the BME dissemination day the following are action points Epilepsy Connections will undertake to ensure that we can continue our commitment towards addressing the health needs of BME people affected by epilepsy;

**Looking ahead... What we will do now**

- Establish and strengthen existing links with GP surgeries, health professionals, BME organisations to ensure that BME people affected by epilepsy can gain access to information about services/information available to them.
- Further development and dissemination of bi-lingual literature amongst BME organisations and all mainstream disability/health and social organisations to continue to raise awareness of epilepsy and Epilepsy Connections service provision.
- Hold future information events for statutory and voluntary organisations

and service providers to promote awareness of epilepsy Connections services, particularly that of the Multicultural Project and to allow for useful networking opportunities.

- Work and engage directly with BME communities to establish trust and rapport and to open up our services by creating awareness.
- To target asylum seeker communities.
- Continue providing awareness to BME organisations to dispel misconceptions and unsafe practice when managing seizures and to lead to the full social inclusion of BME people with epilepsy into their communities.

Epilepsy Connections Multicultural Project has worked hard to develop and deliver culturally-appropriate services and to improve access to information about health and services for BME people affected by epilepsy. We have engaged effectively with BME groups and increased their uptake of our services, but despite these achievements, we do however recognise that there is still a long way to go achieve to the full integration of BME people into service provision and to optimise the health and well-being of BME people with epilepsy and their families.