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disability

Building respect in the  
Scottish community

# ‘What’s out there?’

A project to find out about support services for people with learning disabilities and their families from black and minority ethnic communities

**Executive Summary**

Written by Ex Anima Training & Research Consultancy

## **Acknowledgements**

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## **The Steering Group**

The Steering Group was drawn from the partners in the funding proposal – Scottish Consortium for Learning Disability, The Action Group (Andy Foreman), ARC Scotland (the representative from this organisation withdrew 4-5 months after the researchers were appointed due to other commitments), Glasgow Learning Disability Partnership (Sofi Taylor) and British Institute for Learning Disabilities (Alice Bradley).

Jan Murdoch, SCLD's Public Education and Communication Manager supervised the project on behalf of the Steering Group.

## **The Researchers**

The research was conducted by Ex Anima Training and Research Consultancy – with Ghizala Avan and Farkhanda Chaudhry being the key researchers.

## Executive Summary

This research aimed to find out about 'what's out there' for people with learning disabilities (as defined in main report) and their families from black and minority ethnic communities.

### Methodology

- In depth interviews were carried out with organisations that have engaged with black and minority ethnic communities. Good practice examples were also sought
- Interviews were carried out with black and minority ethnic families who are carers of, or have a learning disability
- Questionnaires were posted and emailed to voluntary and statutory sector agencies (The Scottish Consortium for Learning Disability's database was used and Race Equality Councils across Scotland were also targeted)
- A live discussion (approximately 40 minutes) was held on Radio Awaz in Urdu and English as a way of engaging with people from the Indian and Pakistani communities
- The research included a comprehensive review of literature on learning disabilities and people from black and minority ethnic communities. Although predictably there was not a wide source to draw upon, the literature review highlighted areas such as language, identity and cultural issues; isolation, multiple discrimination, lack of services and lack of access to information

### 1. Main Findings

Key issues emerging from the investigation tallied very much with what was also highlighted in the literature review. Key issues emerged around a number of broad themes. The main findings include:

Interpretation of 'Learning Disability' - In terms of attitudes, meaning and interpretation, terms such as 'learning disability' can hold different connotations in different communities and cultures. Many respondents spoke about the fact that there was a perception that learning disabilities can be cured and were taking additional measures to increase the learning of their child (e.g. paying for additional tutoring). Within communities the lack of understanding of learning disabilities meant that a lot of families were burdened with ideas that they were being punished by God or that the learning disability was the result of black magic. Others reported that it took them significant time to understand the implications of learning disabilities.

Isolation - Because of the lack of understanding of what a learning disability is and fear of what their communities' response would be many families can be isolated from their extended families as well as other members of their community. Children with learning disabilities are often 'hidden' from the extended family and their communities. The isolation from people's own communities could lead to complex issues relating to identity. In one case, a parent found that their child was in denial of his Asian identity until he started mixing with other children from his communities. Being excluded from taking part in religious and cultural activities is another dimension of isolation and a few carers commented on the fact that these religious institutions were not geared to support children with learning disabilities and hence denied access to a very important aspect of the child's learning and cultural experience.

In addition, hostility and isolation may be experienced from the wider communities due to racism and discrimination and a number of respondents shared their experience and fears.

Forced Marriage Issues - Respondents highlighted forced marriage issues as a concern for people with learning disabilities from the black and minority ethnic communities. Organisations working with larger numbers of people with learning

disabilities from the black and minority ethnic communities and community members interviewed were more likely to pick up on this.

Communities which are particularly challenging to reach - Whilst it may be challenging for most organisations to work effectively with people with learning disabilities and family carers from the black and minority ethnic communities, the Chinese and African and Caribbean communities were cited as two particularly hard to reach communities

Partnership Working - In terms of making contact with hard to reach communities, organisations have managed to achieve this by networking and working in collaboration with those organisations that are already being used by these communities. Many organisations valued partnership work, however partnerships need to be developed on the principles of equality and fairness.

Communication Issues – There was ample evidence of the lack of, and inaccessibility of information to black and minority ethnic communities. Interestingly though, virtually all the organisations stated that they can make information available in a variety of languages and have links with interpreting services; however it was not stated how this is publicised to black and minority ethnic communities.

Service Provision – Certain myths and stereotypes still prevail amongst some service providers for example, there is still a belief that black and minority ethnic communities 'look after their own'. This can often mean that these services do not sense the urgency or need to provide for these communities. Also, it was reported that some service providers lacked understanding of how to develop 'culturally sensitive services' and were still struggling to gather base-line information. It was highlighted that there was a lack of workers from black and minority ethnic backgrounds. Where there was a presence it was appreciated by families and people with learning disabilities.

In Councils situated in rural areas where the black and minority ethnic population was low, little effort was made to reach out to these communities

Users' Views of Services - In this study, most of the people interviewed from the black and minority ethnic communities were using services. In fact most organisations which were interviewed were able to put the researchers in touch with some of their clients/users. It is also important to note that in most cases it took many years for the family carers interviewed in this study to actually 'find' services for their children with learning disabilities and themselves in the first place (in one case, it took sixteen years). Once they were linked into a service, this often opened more doors to other services.

'Special Needs' schools in particular were regarded very positively and parents gave many examples of how the schools worked with and supported their child(ren).

People had some positive experiences with social work services; however this was a service which people were most likely to speak negatively about. In general the respondents were very appreciative of the support they were receiving and thought it was immensely invaluable.

Equal Opportunities Monitoring - From the information collated whilst most organisations monitored ethnicity, gender and disability to varying degrees, not all were able to provide a breakdown of service users. Monitoring of ethnicity, gender and disability on management committees and steering groups was poor.

## **2. Good Practice**

There were some interesting approaches and creative initiatives cited as good practice. This included the usage of inclusive imagery and art forms, involvement of black and minority ethnic people in the development of services, involvement of black and minority ethnic communities in projects; supporting families through

advocacy and outreach; working in partnership and bringing together skills, expertise, knowledge and resources; using approaches that reach communities; and creating an attitude of solution focused methods.

### **3. Conclusion**

It is the vision of the steering group for this research and the researchers/authors of this report that the findings from this study will contribute to service providers' understanding of the issues in Scotland. Indeed this is an area requires more attention. The report in particular is intended to be a vehicle for taking forward further discussions on how to strengthen and equip organisations to create better accessibility for people with learning disabilities from the black and minority ethnic communities, and how we can learn from, share and build on good practice.

## Recommendations

### Improving communication and information

- The lack of access to information came up time and time again, therefore greater effort and creativity is required to share information. Not only this but a model of communication which checks out whether the information shared has been received and properly registered (within people's understanding) needs to be developed.
- In addition to a process of checking out understanding, language support for people is essential, not only for those with poor or no English, but also for those who may seem to have a good grasp as a second language.
- Thought needs to be given to the use of language relating to learning disability issues. Some terms such as 'befriender' do not translate well into some of the community languages.
- Multimedia formats are an excellent way to get across messages and information across to communities (e.g. drama/forum theatre, videos/DVD, and documentaries).
- Organisations should build relationships with the black and minority ethnic led media/press and use it to deliver messages and share information (e.g. community newsletters in different languages, websites, community radio's such as radio Awaz and Radio Ramadan, Zee TV).
- There needs to be a general awareness raising in appropriate formats, using appropriate messages amongst black and minority ethnic communities to shift negative attitudes around the subject of learning disabilities.



## **Enhancing connections with communities and agencies**

- Connecting with people in their own environments is a good approach to building contact with people who normally would be isolated. Developing an outreach component to projects/initiatives would yield better results of engagement with people with learning disabilities and their carers from the black and minority ethnic communities.
- This approach coupled with the employment of workers who have networks, links and cultural knowledge of communities they are targeting may ensure the development of appropriate channels of engagement with communities which are particularly difficult to reach (e.g. Chinese and African Caribbean communities).
- The Local Area Coordinator model gets workers much closer to families and enables them to work with the issues that families have. This model needs to be continued and enhanced with more resources and shared as good practice.
- Organisations working in the field of learning disability need to recognise the skills, expertise and ability of black and minority ethnic led organisation to reach people. Positive partnership working arrangements will yield better results. This has been evidenced in some examples of partnership working in this research. In addition, mainstream organisations could work in partnership with black and minority ethnic led agencies to pursue training around culturally sensitive service provision.
- Learning disability organisations could pilot a partnership with some particular religious/cultural institution and support them in finding creative ways of including people with learning disabilities.

- Black and minority ethnic people face greater isolation in rural areas. Due to low numbers of black and minority ethnic communities living in these areas, services may not justify resources to develop initiatives for these communities. However, 'needs' not numbers should be the driving force. It was suggested that partnerships across rural and urban local authorities (where there are larger numbers of people from black and minority ethnic communities), would help to share information and cement good practice. Community Health Care Partnerships (CHCP) could have a role in this as they work across a number of local authority boundaries.

### **Organisational Capacity Building**

A lot of organisations working with people with learning disabilities and more specifically black and minority ethnic communities are rarely well resourced. These organisations need support to build their capacities; in particular support is needed to work with managements committees, Board members and for involving service users.

- Develop role models who can present images and stories about their experiences relating to learning disability issues. Role models enable people to widen their own individual expectations and also challenges the myths and stereotypes that prevail amongst communities and service providers.
- Statutory agencies' contracting processes with voluntary organisations, should be built upon to ensure that organisations that are commissioned to deliver services can demonstrate their services are inclusive and accessible to everyone including people with learning disabilities from black and minority ethnic communities.
- Services need to be 'culturally sensitive' as an understanding of religious/cultural practices will mean a better understanding of how to

engage with black and minority ethnic communities. Also inclusive images, posters and welcome signs in different languages are symbols of accessibility, thus conveying an inclusive and welcoming environment.

### **Planning for the future**

- Demographics are suggesting that particular black and minority ethnic communities have a younger profile and the chances of having a learning disability is greater than the wider population. Therefore, services need to begin to plan today for the future landscape.
- This research did not look at the experiences of other communities such as the travelling communities, asylum seekers and the new communities arriving from the A8 countries (Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Slovakia, Slovenia). It is recommended that this is an area for further investigation.

