

Summary of the research

Project Duration: August 2012 to April 2014

This study is funded by the **National Institute for Health Research, School for Social Care Research** (http://www.nihr.ac.uk/research/Pages/programmes_school_for_social_care_research.aspx).

Aims

To investigate the experiences and perceptions of services (particularly social care services) amongst adults from Black and Minority Ethnic communities who have a learning disability. To use this information to facilitate discussion in a partnership event (see below) to develop solutions and recommendations to improve current practice. To produce a report containing the findings from the interviews and partnership event.

Background

Individuals who have learning disabilities and who are from Black and Ethnic Minority (BME) communities consistently report lower levels of satisfaction with a wide range of services. This study will involve interviews which will focus on participants' understanding of their difficulties and on their experiences of social care services.

Participants

We would like to recruit 30-40 adults (aged 18 years or over) with mild or moderate learning disabilities from any minority population in the West Midlands. All participants must be able to understand enough information about the research to provide informed consent to taking part and will need to have sufficient verbal communication skills to take part in a one-to-one or group discussion.

Recruitment

Participants will be recruited from a range of sources and sites. Some of these will be identified with the help of a specialist advocacy group; others will be recruited through statutory, voluntary and private sector services, including community groups. These will include Local Authority, NHS, education and Third Sector services, but we will also attempt to contact and engage with individuals, groups and families outside of any direct service-provision context.

Interviews

We would like to interview people using group interviews. Group interviews will be employed where possible, because of their advantages in terms of engaging people with learning disabilities in more in-depth discussions. One-to-one interviews can be intimidating for some people with learning disabilities, whereas group interviews can diffuse the perceived 'pressure to respond' and, through the 'scaffolding' effect of sharing experiences with others, can help participants to provide more comprehensive and representative accounts of their experiences and concerns. However, group interviews may not always be practical, or preferred by potential participants, so individual interviews will also be offered. Interpreters and translators will be available, where appropriate.

Issues for discussion in the interviews will include:

- Who does what, for whom
- Clarification of what services are available and who provides them
- The process of getting help from services
- Experiences of services with a specific emphasis on social care
- Relationships with service-providers, especially social care
- Needs met well, needs met poorly, and unmet needs
- What works and what does not work.

Individual interviews will be recorded on a digital audio recorder. Group interviews will be recorded as digital audio and video. The recordings will be used to transcribe what is said during the interviews. The video recordings will be used to help identify who said what during group interviews. These transcripts will then be analysed to identify reoccurring themes, using standard qualitative analytic methods.

Partnership Event

We will hold a partnership event for around 50 stakeholders, including people with learning disabilities, their families, carers, service providers, commissioners of services, third sector organisations, front-line care staff, clinicians, social workers, and managers of services. The event is likely to be held in November 2013 in the West Midlands and last around half a day. At the event, we will present the results of the interviews to stimulate solution-focussed discussion.