

BME service users with learning disabilities

Outline of a research project
funded by the NIHR School
for Social Care Research



Improving the evidence base for
adult social care practice

What do people with learning disabilities from minority ethnic communities want from social care services?

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 including social care services. They are also less likely to be engaged with those services. This suggests that dissatisfaction and low service uptake may be inter-linked, with one negatively affecting the other.

To date, very few studies have explored the reasons behind the dissatisfaction among this group of service users. A wide range of barriers may be relevant, including language issues, a lack of awareness of available services, and a failure by services to be sensitive to aspects of an individual's culture and/or religion. By carrying out research that interacts directly with BME service users with learning disabilities it should be possible to offer some explanations for why satisfaction levels with social care are low, and to consider what might be done to address the problems.

This project

- will carry out a detailed analysis of the social care related experiences of people from BME communities with mild learning disabilities, with a view to improving service providers' engagement with, and provision for, this user group.

It aims to

- engage with a cross-section of people with learning disabilities who come from BME communities in the West Midlands
- elicit and capture their experiences and perceptions of services through the use of appropriate interviewing techniques
- identify, contextualise and describe key patterns of experiences and perceptions (negative and positive) of the participants' relationships with social care
- bring together the expertise of service users, families, social workers, researchers, psychologists, and health and social care professionals to search jointly for solutions to the issues identified.

Research project outline

WHAT IS THE CONTEXT?

Evidence shows that increasing numbers of children and young people from BME communities in the UK are being identified as having special educational needs. For example, the prevalence of learning disabilities in South Asians aged between 5 and 32 years has been reported to be three times higher than in any other community in the UK. This type of higher prevalence may be linked to a poor uptake of maternity services, higher genetic risk factors, and pervasive social and material disadvantage among BME communities in the UK.

At the same time, individuals with learning disabilities from BME communities have been shown to face inequalities in accessing services. While there is a high uptake of GP services, research shows low levels of specialist service uptake. A number of reasons have been suggested including ill-equipped services, language barriers, lack of awareness of services and general dissatisfaction with services.

In the area of social care, there may be specific cultural aspects to dissatisfaction, and/or lack of engagement, with services. For example, members of some BME communities may have interpretations of disability which are very different from the views of health and social care professionals. BME communities may have cultural and religious needs which are not adequately met or understood by services. Language barriers can lead to difficulties in communication with service providers and thus to low service uptake. Stigma can affect service uptake if families want to access services but fear they will be judged by their community. There may also be complex family circumstances that are not fully understood by health and social care professionals. Such issues lead to specific challenges for the methodology of a project such as this (see Box).

The UK Government has recognised the need to develop culturally-sensitive disability services in policy documents such as the National Carers Strategy, Learning Difficulties and Ethnicity: A Framework for Action and Valuing People. However, research has demonstrated a continuing failure to consider BME communities when planning and implementing services.

Project challenges

The conduct of this project will have to meet key challenges:

- not all potential service-users will be engaged with services, so it will be important to identify participants through a range of organisations
- BME incorporates diverse communities, and it will be important to include different BME communities and to produce an analysis that is sensitive to different backgrounds
- many potential participants may be reluctant to take part if they have had poor experiences of formal organisations
- research interviews will need to be carried out in the appropriate languages or through high quality translators
- many participants may not distinguish between 'social care' providers and other sources of care and support, such as health care.

To date, very few studies have explored satisfaction with services among people with learning disabilities. The majority of the research that has been carried out was conducted with carers, particularly parents, and among the majority UK population. The voices of service-users, particularly those from BME communities, have rarely been heard. This may be due to the methodological difficulties in conducting research with individuals with communication difficulties. However, a number of projects have found that people with learning disabilities can often give more detailed accounts of their lives than carers. More recently there is evidence that approaches such as Interpretative Phenomenological Analysis (IPA) can be used effectively with this client group.

HOW WILL THE PROJECT WORK?

The focus will be to collect accounts from a cross-section of people with learning disabilities from BME communities in order to understand better the nature of their dissatisfaction with social care services.

Research project outline

STAGE 1: Recruitment

Between 30 and 40 participants will contribute to the study. Participants may be anyone with a mild learning disability, from any minority population in the West Midlands and will be recruited from a range of sources and sites. The project team recognises the challenge of recruitment to a project of this type and will make use of existing links with social care staff and other practitioners, and with voluntary and community groups. In addition, a specialist advocacy group will be involved. These strategies will help identify and recruit a broad range of service users and non-service users from both urban and rural environments.

STAGE 2: Interviews

Group interviews will be carried out where possible because of their advantages in 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 interactions can diffuse the perceived 'pressure to respond' and, through the effect of sharing experiences with others, can help participants to provide more comprehensive and representative accounts of their experiences. However, the research team is aware that group interviews may not always be practical, or preferred by potential participants. All participants will therefore have the option of being interviewed individually.

Issues for discussion will include:

- who does what, for whom
- what is a 'service'
- clarification of what services are available and who provides them
- the process of securing 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.

In any interview where language is an issue, care will be taken to provide skilled interpretation services.

STAGE 3: Data analysis

The analysis will focus on understanding the issues from the participants' points-of-view and will be conducted in two phases. It is anticipated that some of the data (particularly from interviews with service users who already know each other) will be rich and substantive. Interpretative Phenomenological Analysis (IPA) will be used where the data provides detailed first-person accounts of experience. IPA is a well-established approach in psychology to qualitative data analysis, and is specifically designed for complex data, small samples, and the interpretation of experiential material.

Other data may be less rich and contain accounts that are less coherent in their narrative structure, or more instrumental or factual in focus. This is more likely to be the case for individual interviews, and for groups who are meeting for the first time. Template analysis will be used for these accounts. It allows for a more 'top-down' form of analysis by asking specific questions of the data, in this case based on the IPA findings. The template will include prompts for identifying new themes and 'deviant cases' so that the second phase is more than simply confirmatory of the first phase analysis results.

STAGE 4: 'Co-design' event

The project's findings will be fed into a 'co-design' event that brings together service users, service providers, academics and other stakeholders to address the issues raised by the research participants. The event will facilitate a joint process of developing clear plans for how to address the identified problems, who would do what, and on what timescale.

Project publications

An accessible project report will be published nationally and shared locally with individuals and organisations who contributed to the research. Other publications will include papers in peer reviewed journals and open access journals, an administrative report, and a note reflecting the methods used and any lessons learnt. The ideas generated in the co-design event will also be made available in academic and accessible formats.

Research project outline

HOW DOES THE PROJECT FIT THE AIMS OF THE SCHOOL FOR SOCIAL CARE RESEARCH?

The project will identify patterns in experiences of learning disability services which are common to people from BME communities as a whole, but it will also draw out cultural variations, in terms of the differing experiences and needs of particular cultural groups.

Publishing the outcomes of this exploratory study, including the personal experiences of participants in their own words, will improve the evidence base that influences social care practice. It will help social care practitioners recognise the relative importance of different perspectives and should alert them to a range of potentially competing agendas.

The project's 'solution-focused' approach is designed to identify positive changes that can be made and the project team envisages being able to contribute to the development of advice on best practice for social care providers when working with people who are from BME communities who also have learning disabilities. There will also be specific recommendations such as how best to develop and reorganise existing social care services for specific groups of people.

The Research Team

Dr Michael Larkin, Senior Lecturer, School of Psychology, University of Birmingham will be responsible for the research design and overseeing the analysis of the data. Dr Larkin is an experienced researcher, with particular expertise in Interpretive Phenomenological Analysis (IPA).

Dr John Rose, Academic Director, Clinical Psychology Doctorate programme, University of Birmingham and professional lead for psychology in Dudley PCT, will liaise with local clinicians and support the recruitment of participants with the aid of Dudley Advocacy. Dr Rose is an experienced clinical psychologist who has worked with people with learning disabilities for over 25 years.

Dr Biza Stenfert Kroese, Senior Lecturer, School of Psychology, University of Birmingham, will manage the project on a day-to-day basis and be involved directly with the research. She is a clinical psychologist who has worked with people who have learning disabilities in the NHS.

Gemma Unwin, Research Fellow, School of Psychology, University of Birmingham will be responsible for the day-to-day running of the project, in particular, fieldwork: liaising with potential participants and conducting interviews. She has over seven years experience of research in the field of learning disabilities.

Project title:
People with learning disabilities from black and minority groups: an exploration of their experiences and views of social care services

Timescale:
1 January 2012 to
30 April 2014

Budget:
£140,462

Contact:
Dr Michael Larkin,
Senior Lecturer,
School of Psychology,
The University of Birmingham,
Edgbaston,
Birmingham
B15 2TT

Telephone:
0121 414 6036

Email:
m.larkin@bham.ac.uk

