

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

Our focus on interviewing people with learning disabilities is rare and could provide missing insights, adding to what is already known through work with carers and families.

Social care services are sometimes not taken up as frequently or as consistently as they ought to be by people with learning difficulties from BME communities. Why? Anecdotally, all kinds of reasons are suggested by research, services users and providers. Sometimes, services are said not to be culturally sensitive or people feel that a service is simply not meant for people like them or their families. People may not be aware of services. Sometimes complaints are less about the services and more about the process of getting them. More recently, there have been big changes in the way services are funded and accessed, following cutbacks, so some people have lost access that they previously enjoyed.

A team from the University of Birmingham, funded by the SSCR, is researching the diverse reasons why this client group may feel let down. 'There may, for example, be cases where Muslim service users have been invited out for a meal with other service users but been effectively excluded because the meal has not been halal,' explains Dr Michael Larkin, who leads the team. 'Alternatively, an event might be put on with insufficient thought given to managing mixed gender presence. For example, some service users



might be excluded because there is no chaperone. A recurrent issue is the patchy availability of interpreters.'

This can be particularly true for people with learning difficulties who still live with their parents, where it is important for the family to understand the purpose of a service and what it can achieve. 'A good example,' says Dr Larkin 'might be an interpreter not familiar with health issues who may translate a sensitive term like "learning disability" into terms that you would not choose, that might be seen as derogatory, running the risk of making

'Good services can make a positive difference to people's lives. Conversely, if services aren't accessible or appropriate, then people may be marginalised, and their wellbeing may be put at risk.'

Dr Michael Larkin, researcher

the family feel stigma by engaging with the service. If the engagement is not made properly, a young person might miss out unnecessarily on something important.'

The consequence of people not accessing services can be blighted lives, adds Dr Larkin. 'The research provides opportunities to help people to live fulfilled lives and feel part of the world and contribute to it in meaningful ways. If we don't use the resources in the right ways, then we are left with people marginalised, excluded and at risk.'

'If people with learning disabilities are disengaged from services, one of the knock-on effects is that people may not be accessing physical healthcare adequately as well. Likewise, if people don't reach their educational potential, then they may be at risk when they have to live independently. So, there are many vulnerabilities to which people with learning difficulties are exposed if they are not engaged with the world and involved with it.'

Finding out what is going on is not easy, starting with establishing a person's cultural identity. The team has been

developing tools for engaging with people with learning difficulties who may not be used to ticking demographic boxes. A 'culturalgram' has been developed in which people relate information about their family, what language is spoken at home and what religion they believe in.

'We are also engaging with local service providers – mainly third sector organisations,' explains Dr Larkin. 'One of our challenges is reassuring them that we are interested in people's general perspective on access to services and that we are not evaluating any particular provider. We are also interviewing staff from organisations that provide social care. We want to understand their experience of working cross-culturally – both the benefits and the challenges. It is a perspective that is often missing from previous research.'

The team's goal, at the end of the research, is to bring people with learning disabilities together with service providers in a partnership event to do something to tackle the issues and help offer routes to better engagement and services.

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

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