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Learning Disabilities and BME Communities: Principles for Best Practice

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Introduction

The purpose of this briefing is to present some ideas for best practice in the effective delivery of learning disability services to users from BME communities. The briefing draws on the findings of qualitative research undertaken by INLOGOV for a local authority seeking to improve the historically low uptake of these services by individuals from BME communities. After briefly providing some detail of the broad findings from this research, the briefing uses these themes to develop principles of best practice in this field, with a particular emphasis on service-user involvement.

The Policy Context

Individuals from BME communities are often underrepresented in the uptake of learning disability services. For example, while the prevalence of learning disability is three times higher than average in South Asian populations compared to the rest of the population and is also significantly higher in the African Caribbean community (Amzi et al, 2006), in a case study of learning disability service users in an English county local authority area undertaken by INLOGOV in 2012, just 0.2% of clients were recorded as from South Asian backgrounds, and that 0.05% of the Black Caribbean group are service users.

Families from BME and emerging communities who are caring for someone with a learning disability face not only problems encountered by all carers, but also a number of potentially compounding issues, including racism, health inequalities, culturally inappropriate services and language barriers. This is sometimes referred to as double or triple discrimination. The Government's three year strategy for people with a learning disability, *Valuing People Now* (2009), emphasises the need to make specific changes to make sure that the needs of the most excluded groups are met – including people from BME backgrounds and emerging communities.

Engaging users in helping to shape and develop services through 'service user involvement' or 'co-production processes' is now an intrinsic part of the public services policy agenda. This has also been seen by government as an essential component in helping to revitalise and renew local democracy, improve trust in public institutions, enhance community cohesion and encourage active citizen culture. The previous Government's White Paper on community engagement, *Communities in Control: Real People, Real Power* (2008) set out new duties for local authorities to engage with and empower local people. Since April 2009, local authorities have had a duty to inform, consult and involve communities in local decisions, policies and services. Various national policies demonstrate central government's drive towards involving communities (e.g. *Local Government and Public Involvement in Health Act, 2007*; *Sustainable Communities Act, 2008*; *Planning for a Sustainable Future, 2007*).

In a similar vein, 'Putting People First' (2007) has now become a shared vision for transforming Adult Social Care. This vision, and the underlying concepts, has been growing in importance within social care policy over the last decade and initiatives such as the Direct Payment Scheme and Supporting People and the In-Control initiative have all focused strongly on the needs of the individual. More recently, the new Social Reform Concordat has committed authorities to a system of Adult Social Care which is based on the values of being healthy, staying well, and living independently, while upholding the right to self-determination and equality of citizenship.

In addition, recent policies have demonstrated a complimentary focus on delivering services that are responsive to local need and also subject to local level accountability. For example, the Government's move towards clinically-led commissioning (Health and Social Care Act, 2012), under the provisions of which GPs will commission services for their local area through Clinical Commissioning Groups, demonstrates a strong focus on delivering services which are responsive to local communities and local needs. Additionally the Localism Act (2011) again emphasises this central focus on local community empowerment and local community accountability. Such policy measures demonstrate an ongoing commitment to delivering services in local communities which meet local needs.

Barriers to service use

While such a focus may be beneficial in terms of tailoring services to the needs of particular BME communities, there are complex challenges involved in designing and commissioning services in such communities. We completed qualitative research in the local authority area previously referenced, to examine the barriers to service use by individuals from BME communities and to explore the scope for more collaborative and integrated approaches to commissioning for the delivery of more suitable learning disability services for BME and emerging communities. The results of this research reveal a number of key themes, which we now briefly summarise.

Culture, ethnicity and access to services

In a survey of stakeholders in the case study location, 64% perceived culture and ethnicity to play a role in how learning disability services are perceived and accessed by potential users. Further qualitative work highlighted some of the reasons for this – for example, it was evident that learning disability services are perceived in different ways by different communities, and that people with learning disabilities from BME groups had experienced stigma, prejudice, and often exclusion from their community. There was also an apparent problem of trust, where potential BME service users and their carers feared engaging with services; and also the view that often small scale needs of BME service users are overlooked, for example the provision of adequate funds to purchase 'specialist' foods that are not readily available in mainstream shops.

Information and communication

Throughout the research, there was a general consensus that the best way to improve access to learning disability services for BME communities is through providing more information and improving communication channels. 100% of participants in the stakeholder survey believed that more publicity and increased awareness would improve access to those services for BME groups. Two different forms of information and communication were highlighted by the research, with different yet related purposes. On the one hand, information and communication is important in terms of increasing knowledge and awareness of learning disabilities and the service available, in order to reduce stigma and prejudice, and to increase the accessibility of services to users and carers who may have very little awareness of the choices available. On the other hand, information and communication is seen as vital in increasing service user and carer involvement in the production of services, which would deliver more responsive service that are appropriate to the needs of BME service users specifically.

Building on contacts

The main challenge in terms of increasing information and communication is that commissioners of services in the case study location were relatively unaware of the numbers and location of individuals with learning disabilities in BME communities. It was therefore difficult for them to target initial efforts at increasing communication and awareness of services, and to begin to develop the kinds of links with service users for the co-production of services which will enable them to develop more appropriate and responsive services in the right locations. However, one issue which became apparent across the research was the importance of utilising existing community structures. Returning to the importance of trust in developing relationships, it would seem that more longstanding and robust relationships are key to enabling more individuals within BME communities to make use of learning disability services, and to better understanding the needs of those individuals in relation to service provision.

Service user involvement

Engaging with BME communities about the types of services which would be most appropriate for them represents a key way of increasing service use by people from such groups. However, the problem exists that it is very challenging to engage those not currently using services in any form of consultation or co-production, because those individuals do not currently have any contact with service providers, yet they are the exact people who will need to be contacted. Indeed, commissioners interviewed as part of the research reflected on how a shift towards local and GP-led commissioning could impact on the ability of vulnerable groups within BME communities to be heard, given the limited community representation on Health and Wellbeing Boards and the limited capacity of Healthwatch.

However, the research also found that both the local authority community team and third sector organisations working within the case study location had significant success in engaging with BME communities – for example, they understood that the

best way to build up contacts and dissemination information is through word of mouth. These individuals did, however, raise concerns about making contact with BME communities meaningful. During the course of the research they reflected on how often the BME communities could become switched off to any kind of regular engagement because often there is a lack of follow-up by service providers. Individuals are asked the same questions on numerous occasions, and simply see little to no benefit in the services they receive, or any follow-up in terms of what the consultation exercise has achieved.

Silo working

Silo working presents a complex challenge to engagement. As already highlighted, individuals may have limited trust in service providers and may be reluctant to engage with them for reasons stemming from this lack of confidence. Increasing trust is likely to occur through awareness raising and through positive experiences where engagement with services is increased, and this will be a gradual process of improvement. However, silo-working impacts significantly on the extent to which this trust in services and providers can be built. For example, building partnership-working between different teams and organisations focused on learning disability services, BME communities, and the two combined would greatly increase opportunities to develop knowledge of the scope of people with learning disabilities in a particular locality. It would additionally mean that the sometimes repetitive nature of consultation and engagement is reduced, with information sharing leading to more productive engagement with clearer feedback mechanisms.

Best practice in BME learning disability service delivery

The previous section highlighted overall that two inter-related issues are crucial to increasing uptake of learning disability services by individuals from BME communities. One of these is the need to encourage more people to access services, and the other is the need to get them involved in designing the services to be delivered. These two are interlinked, because encouraging individuals to access services rests on providing services which are appropriate to their needs, and this will best be achieved through BME service user involvement in the design process.

This section presents findings from research into best practice in delivering learning disability services to BME communities. It supports the overall conclusion that addressing the challenges identified hinges on improving information and communication.

Informing potential service users

Developing and disseminating appropriate information will be beneficial in terms of increasing the use of learning disability services by individuals from BME communities, and in terms of increasing awareness of learning disability which can reduce the prejudice and stigma which is often attached to it. An important aspect of this work will be to deliver the right information in the right way. It is important to disseminate information both in terms of defining what is meant by learning disability,

and to highlight the ways in which people may access further information and services. However, a particular challenge here is that knowledge of what information is to be useful to people will be limited where there is current limited engagement with BME communities themselves.

One option to overcome this problem is to co-produce the literature on learning disabilities to be distributed to BME communities with current service users from BME communities and their carers. Rogers and Namaganda (2005) reflect on this as a useful way of developing information resources which are well suited to diverse cultural, religious and gender identities, because they are developed with the direct involvement of those who the information is aimed at.

Another issue is that information needs to be provided in the right format. Once produced, it should be translated into as many different languages as is deemed necessary. Once again, this is challenging without thorough knowledge of the language needs of potential service users. However, Enfield Council¹ has tackled this by translating information into a variety of languages, and then developing a mechanism through which learning disability service staff can feed back on any additional language needs identified during their work with new service users.

Further, information should be provided through many different means of communication. Midland Mencap, a third sector provider of learning disability services in Birmingham, set up a marketing strategy aimed at BME communities in order to increase service use (Fox-Kirk, 2009). They approached this through a 'multi-channel' strategy, with posters in a range of formats, and numerous talks being given about learning disabilities and the services available in key community locations.

Developing a volunteer strategy

A key aspect of building contact with BME communities and increasing uptake of learning disability services highlighted in the case study research was contact-building. It was shown that building on existing contacts and structures within local communities offered a potentially very fruitful way of reaching potential service users in BME communities, and of developing mechanisms for service-user involvement. One way of achieving these aims is to develop a volunteer strategy which can harness the potential of word of mouth communication to increase awareness and participation.

A volunteer strategy works on the basis of recruiting a number of volunteers who are based within target communities and have a range of contacts within those communities. Those individuals then work to communicate with people they know, about learning disability services that are available. The individuals are already embedded within communities and therefore already have contacts to build on. Such a strategy was followed by Midland Mencap, who also saw important additional gains in terms of the training and development opportunities this offered to the

¹ Information on best practice examples was gathered through the individual websites of organisations, and from Chris Hatton's review of best practice in improving learning disability services for people from BME communities (Hatton, 2007).

volunteers who were generally already carers themselves. The carer volunteers developed networks within their communities, and were able to both champion services in their local area and become advocates on key representative forums.

Similar volunteer strategies have been used in other contexts, and have been seen as very successful in reaching both BME and newly emerging communities. For example, Herefordshire County Council has in recent years had to find ways of developing services for its Eastern European population, which arrived in a very short period of time and for which the Council had very limited awareness of needs. The Council successfully ran a project titled 'Herefordshire 100' (Herefordshire Council, 2009), in which it recruited and trained 100 volunteers from BME and emerging communities to go into their communities and complete questionnaires with a set number of relevant people known to them. The questionnaires asked them about their satisfaction with services they had accessed, and what kinds of services would be useful to them. Using community volunteers overcame cultural and language barriers, and made it possible for the Council to identify the needs of individuals who were almost entirely hidden to them.

Clearly, proposals such as these would only be an initial step in developing improved contact with BME communities and engaging with potential service users. However, they offer opportunities to build relationships, to increase understanding of needs, and also to deliver increased trust – as people see the volunteers as champions for the services, and the services as responsive to their needs.

An overall strategy

The further development of this service user involvement, and taking forward the kind of ideas for practice outlined in this briefing, depends on robust incorporation of BME inclusion issues into the strategic planning of services. Some councils have worked to develop strategic working groups which are dedicated to issues relation to the use of learning disability services by BME communities.

For example, Birmingham City Council set up a working group which brought together users, carers and staff to work to ensure the strategic direction of the service commissioned could appropriately meet the needs of BME communities. They created a direct relationship between the discussions held there and the overall strategic direction of commissioning by having the Director of the Learning Disability Partnership Board sit on the working group. Similarly Coventry's Partnership Board has incorporated a representative of BME service users and carers as co-chair of the Board, once again to ensure that issues surrounding BME inclusion are directly incorporated into the commissioning structures of learning disability services.

Building the consideration of BME inclusion at a strategic level highlights the potential to develop a representative role for service users and carers to express their needs and wishes. This is also evident in relation to the volunteer strategy and the co-production of information. A middle level of representation, between the strategic oversight and the very local community engagement, offers the potential for individuals to act as representatives from their community in these forms of activities. For example, Croydon has developed a form of 'bi-lingual advocacy' through which key representatives are able to engage with those unable to communicate in English

and then communicate their needs and concerns to key individuals responsible for service commissioning.

Similarly self-advocacy groups such as those set up in Leicester, where BME users work together to come up with ways of improving their services, offer useful ways of engaging with BME service users. Concerns were highlighted in the case study research about a lack of meaningful engagement with BME service users; however, taking this kind of three-tier strategic approach (volunteer strategy – self-representation – strategic contribution) should reduce repetition and improve regular feedback mechanisms.

A BME development worker

Many of the examples of best practice that were utilised to highlight these options for improving uptake of services by, and engagement with learning disability service users, are also those which promote the use of a BME development worker to take these initiatives forward. The most detailed example of this can be found in relation to Midland Mencap, where a BME development worker was recruited on the basis that he had previous experience of working with vulnerable groups, had some additional language skills and significant experience of working with diverse communities. He also had existing links with the local communities.

This BME development worker was provided with some guidance in terms of what was hoped to be achieved, but he was allowed to experiment in terms of methods of engagement, building on his contacts. As previously noted, he gave talks on learning disability services in a range of locations, and also developed strong relationships with community organisations in order to raise awareness of services. Such an individual is then also a central point of contact for the wide range of individuals working with those with learning disabilities and/or from BME communities, and can work specifically to facilitate service-user involvement, to develop understanding of needs, and to overcome barriers to service use.

Summary

This briefing has described an approach to increasing the use of learning disability services by BME communities, and also increasing the involvement of those service users in the design and commissioning of services, which recognises that the best way to reach BME groups is through face to face contact and utilising existing contacts and networks to build up stronger relationships. This can then build up stronger relations which can increase opportunities to both get more people to use services, and to provide a more detailed understanding of what kinds of services will be appropriate through an ongoing relationship for service user involvement.

Examples from best practice have demonstrated how targeted information campaigns, together with a rigorous strategy for increasing service user involvement at all levels, is the best way to seek to achieve these aims. The examples further highlighted that the recruitment of a BME Development Worker is likely to be very beneficial to BME engagement with learning disability services.

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