Towards race equality in advocacy services: people with learning disabilities from black and minority ethnic communities

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Key messages

1 People with learning disabilities from black and minority ethnic communities face 'double discrimination' in accessing public services

2 The concept of advocacy is itself problematic as it may not be widely or fully understood nor easily translatable for many black and minority ethnic communities

3 Developing cultural knowledge is crucial in working towards race equality in advocacy services. The advocacy practitioner must, through training and personal development, be able to respond appropriately and constructively to a black and minority ethnic client's experience of racism

4 To promote full and equal access to public services, it is essential to meet the language requirements of those black and minority ethnic individuals who need to use advocacy services.

Introduction

People with learning disabilities from black and minority ethnic communities have long been recognised as one of a handful of social groups who are *'least often heard and most often excluded'* (DH, 2009, p. 14) and they are almost always under-represented in the client base of both voluntary and statutory service providers (Mencap, 2009). Their experience, and that of their families who care for them, has certain distinguishing features, notably:

• lack of accessible information regarding both learning disabilities and the support services available to them;
• lack of culturally appropriate services in terms of, for example, respite provision, mixed gender activities and dietary needs;
• stereotyping: viewing black and minority ethnic communities as a single, homogeneous group, thus overlooking differences within and between communities;
• lack of social contact: the taboo attaching to learning disability in some Asian communities results in parents receiving very little support from within their communities;
• difficulty understanding the system: as one mother of two children with learning disabilities comments, *'I don't know what the rules are and I don't know who can tell me the rules'*.
 (Adapted from Mencap, 2009, pp. 7-15)

Gill and Badger (2007) estimate at least 60 000 people with learning disabilities from black and minority ethnic communities in the UK. However, despite almost a decade of policy and legislative measures aimed at combating health and social inequalities, it is hard not to agree with the assertion by Mencap (2007) that people with learning disabilities encounter institutional discrimination in their dealings with health and social care services.

Mencap's 2007 report, *Death by Indifference*, illustrates how institutional discrimination can result in the avoidable death of patients with learning disabilities. It describes the health care experiences of six people with

learning disabilities who died between 2003 and 2005 while in National Health Service care. The report triggered an official investigation into the deaths (LGO/PHSO, 2009), a striking finding of which was that none of the six families concerned had had any contact with advocacy services in the period leading up to the death of their relative. The investigation found that *'[w]hile parents and families undoubtedly advocated strongly on behalf of their family members, it is possible that independent advocates might have provided the people concerned and their families with additional support,* **or even have affected some of the outcomes'** (LGO/PHSO, 2009, p. 27, emphasis added). The clear implication is that advocacy intervention could potentially have saved lives.

Advocacy services can facilitate access for vulnerable groups to public services. This paper sets out the arguments for providing appropriate and effective advocacy services for people with learning disabilities from black and minority ethnic communities and thereafter considers the challenges that advocacy service providers (as opposed to self-advocacy groups) must confront if they are to offer such support to this vulnerable group.

Double discrimination

1

Research findings from a range of health and social care settings indicate that people from black and minority ethnic communities encounter disadvantage and discrimination in seeking the care to which they are entitled (see Butt and Mirza, 1996; Alexander, 1999; Mir *et al*., 2001). Indeed, Bowes and Sim (2006, p. 1217) refer to *'the systemic exclusion of people in BME groups'* from mainstream services. For these individuals with learning disabilities, such disadvantage and discrimination makes them especially vulnerable, to the extent that they face a 'double discrimination' in accessing health and social care (Butt and Mirza, 1996; National Autistic Society, 2007; Mencap, 2009). Indeed, a female from this group would face triple discrimination (Mir *et al*., 2001). These disadvantages are not simply cumulative but are simultaneous, multiple and interlocking. Begum (1995) argues that this type of layered or interlocking discrimination exerts its own particular effect on individuals and that this is greater than the sum of its parts. The interlocking barriers that black and minority ethnic individuals with learning disabilities may encounter are numerous (Mir *et al*., 2001; Joseph Rowntree Foundation, 2002; Bowes and Sim, 2006; Mencap, 2009). Principal among them are:
- racist attitudes;
- institutional racism;
- disablist attitudes;
- institutional disablism;
- poverty;
- language;
- lack of terminology in some community languages to describe learning disabilities or to differentiate between, say, learning disability, autism and mental illness;
- lack of cultural knowledge;
- health professionals' assumptions and attitudes;
- poor quality of care.

In light of the *'substantial inequalities and discrimination'* (Mir *et al*., 2001, p. 2) faced by black and minority ethnic communities in accessing health and social care, a person with learning disabilities from a black and minority ethnic community is likely either to remain cut off from public services or to receive inappropriate support. Indeed, it is estimated that over 75 per cent of people with learning disabilities from black and minority ethnic communities are struggling without any form of support, while fewer than 25 per cent are known to services (Hatton, 2005). For this reason, advocacy services, readily accessible and well delivered, are required which can support an individual with learning disabilities from a black and minority ethnic community to overcome these barriers and to access timely and appropriate health and social care.

2   Advocacy: differing perceptions and understandings

'Mainstream' or 'generic' advocacy services, such as health and social care services, are not created in a cultural vacuum. At both service and advocacy practitioner levels, ingrained racist attitudes and practices can, for vulnerable individuals from black and minority ethnic communities, create barriers to accessing advocacy. Moreover, Rai-Atkins *et al*. (2002) and Fazil *et al*. (2004) note that the advocacy movement has been a predominantly 'white' movement based on 'Western' notions of advocacy, suggesting that the emphasis on autonomy and empowerment of the individual does not fit so well in cultural contexts that have the family rather than the individual as a focus (Bowes and Sim, 2006). As Bowes and Sim (2006, p. 1211) note, *'[t]he development of advocacy as a public "good" enshrined in policy has not … been informed by the views and experiences of BME communities'*. Indeed, the concept of advocacy itself is problematic, because it may not be widely or fully understood by some minority ethnic groups, for whom the term may not be easily translatable, and expectations from clients and families may not match organisational aims (Rai-Atkins *et al*., 2002; Quinn *et al*., 2003; Fazil *et al*., 2004). In this context, it may be that advocacy service providers need to identify different, more culturally tailored ways of describing the services they offer.

For many service providers, employing black and minority ethnic advocates is seen as a way of dealing with this lack of agreement over what advocacy is and what it can do, with the result that these advocates can be seen as a 'quick fix to the minority issue'. At the same time, majority community advocates can feel disenfranchised from working with black and minority ethnic clients. The contribution of black and minority ethnic advocates should be seen as part of the process of promoting race equality, rather than as an end in itself. 'Indeed, having ethnically matched advocates is not always ideal. For some, *'the embeddedness of the [community advocacy] groups in local community life could present problems – for example, breaches of confidentiality linked with undesirable outcomes in terms of intra-community relations'* (Bowes and Sim, 2006, p. 1219). In addition to confidentiality, issues to do with over-identification and shared, unexamined assumptions may also qualify the intra-community advocacy relationship (Richardson and Fulton, 2010). Equally, for the client, *'feelings of shame may be sharply felt when confronted by a worker with shared cultural understandings'* (Sangster *et al*., 2002, p. 34). Nonetheless, Sangster *et al*. (2002, p. 34) found that *'while BME workers were seen to have considerable value as symbols of accessibility and trust, their value was seen to extend well beyond the symbolic. BME workers were seen to have ready access to BME social networks and were identified as an important source of authentic knowledge and experience'*.

3   The importance of cultural knowledge

Williams and Rucker (2000) argue that negative stereotypes about minorities are an important explanation for health care inequalities (indeed, as set out in Section 1 above, for the black and minority ethnic individual with learning disabilities, such negative stereotypes may hinge on their disability as well as their ethnicity). At the practitioner level, negative stereotyping can lead to prejudice and discriminatory behaviour. For example, failing to offer respite care services to South Asian carers for people with learning disabilities, because they are seen as 'looking after their own', denies choice and potential opportunity to the carer (see Butt and Mirza, 1996). Seeleman *et al*. (2009, p. 232) state that *'cultural background, among other factors such as religion, influences people's perceptions of health and health care, their frames of reference, and their expectations. Awareness of how this might be of influence – instead of mere knowledge about the cultural practices or beliefs of specific ethnic groups – and an appreciation of this factor helps [practitioners] deal effectively with cultural issues'*.

Developing cultural knowledge is of fundamental importance in working towards race equality in advocacy services; indeed, an important component of developing cultural knowledge is the recognition of inequalities in

power (Papadopoulos *et al*., 2004, p. 113). It is worth noting here that a black and minority ethnic client with learning disabilities may bring to the advocacy relationship current, ongoing experience of racism, the effects of previous racism, or both. Developing cultural knowledge is thus not without its challenges. As part of the process, the advocacy practitioner must fight the instinct to overlook instances of racism or to underplay the relevance and significance of cultural difference. As O'Shaughnessy and Tilki (2007, p. 74) have it, citing Macpherson (1999), *'[f]ailure to recognise cultural differences, a feeling that these differences are not significant, or that attention to individualised care will transcend them can result in discrimination, which although unintentional, potentially constitutes institutional racism'*. For the advocacy practitioner, this is the defining challenge of actively, personally working towards race equality in advocacy services: the task demands of the individual a consciously modified relationship to themselves and to the world. The advocacy practitioner must examine, strive to understand and thereafter modify where necessary the ways in which they respond to the people and situations they encounter in their daily lives, personally as well as professionally. It is the comprehensiveness of the change required, its breadth and depth, its conflation of our personal and professional lives, which makes the individual pursuit of race equality so challenging and so potentially problematic, yet also so potentially rewarding. In identifying and challenging prejudice and discrimination in themselves as well as in those around them, advocacy practitioners are working towards race equality in advocacy services and, in so doing, promoting and defending their clients' rights.

Meeting the language needs of black and minority ethnic clients
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Mir *et al*. (2001, p. 42) state that meeting the language needs of black and minority ethnic individuals who require advocacy to gain full access to public services, is crucial and that, regarding printed material, *'[t]ranslations that are provided in a vacuum and not linked to staff who can respond to queries are not entirely useful if language remains a barrier to applying for services'*. Moreover, where these resources are made available is also significant, with culturally appropriate locations, such as places of worship, community centres, women's groups or GP surgeries, achieving a greater impact on awareness and uptake of services. The choice of medium also plays a role, not least for those who lack literacy skills. Local press and black and minority ethnic community radio, television and publications, as well as video, audio-tapes and face-to-face communication, can all be effective channels. Concerning printed material, it is important to recognise that power imbalances may have the effect of restricting who has access to gaining literacy skills. For example, male privilege in terms of access to educational opportunities can result in further marginalisation of women. Therefore, even access to 'accessible information' may be filtered through power differentials defined by, for example, gender, socio-economic status or caste (Richardson and Fulton, 2010).

Language barriers in face-to-face advocacy service delivery can be all but insurmountable, not least given the lack of terminology in some languages to refer to, for example, advocacy or learning disability. As such, the services of an interpreter may be required. While it may be unethical and unprofessional to use children or other family members as interpreters, nonetheless this is often how black and minority ethnic clients seek to overcome language difficulties. This risks children being exposed to inappropriate life experiences at too young an age. Additionally, where mature family members are used as interpreters, bias, family loyalties and power imbalances may compromise the advocacy interaction. Where language support is sought from community groups, there may be similar concerns, including concerns that confidentiality may not be maintained by the person in the interpreting role. Ultimately, interpretation in the context of advocacy service provision must be acknowledged for what it is, a professional service with a significance and a cultural and technical knowledge base that surpass mere linguistic ability: *'the interpreter is the person who makes the link between two different languages and cultures … [who] makes sense of unusual questioning [and] helps contain feelings'* (Raval, 1996, p. 36).

Conclusion

In light of increasing cultural and ethnic diversity at all levels of UK society, there is a pressing need to work towards race equality in advocacy services as a means of ensuring that all communities enjoy equal access to public services. Health and social care practitioners are having increasingly to interact with clients who may have limited or no English language abilities, different care-seeking behaviours and different expectations of health and social care. Black and minority ethnic groups now account for 73 per cent of the UK's total population growth, while their distribution is becoming less geographically concentrated (POST, 2007). At the same time, the number of adults with learning disabilities (aged fifteen and over) is set to rise by 11 per cent between 2001 and 2021 (Emerson and Hatton, 2004). Within this increase and time frame, the number of adults with learning disabilities aged over sixty is predicted to increase by 36 per cent (Emerson and Hatton, 2004). This evolution is likely to place a proportionately greater burden on advocacy services given that this client group is progressively less likely to have family members to advocate on their behalf. People with learning disabilities from black and minority ethnic communities are thus growing in number and becoming more geographically dispersed, making the work of advocacy service providers ever more challenging; indeed, the rate of black and minority ethnic population growth is fastest in rural areas. The time is therefore ripe for advocacy services to redouble their efforts to reach and advocate for this excluded social group.

Resources 1

Advocacy Resource Exchange (ARX)
www.advocacyresource.org.uk/Home
ARX is a national advocacy organisation that has a useful 'find a local advocate' service. It also runs a project called Supported Voices, which supports black and minority ethnic advocacy across London and provides practical training and support for advocacy schemes wanting to increase their accessibility to people from black and minority ethnic communities. On the publications section of the website's resources page, there is a link to a useful report titled *Developing BME Advocacy*, a resource that supports advocates in building sensitive and productive partnerships with their clients from different cultural and ethnic backgrounds.

Association for Real Change (ARC)
www.arcuk.org.uk/1/default/association+for+real+change.html
ARC is a membership organisation that supports providers of services to people with a learning disability to promote real change. On the extremely comprehensive website's publications page there are links to a number of resources for black and minority ethnic communities, including a guidance manual, titled *Services for All*, on how to provide culturally appropriate services for people with learning disabilities.

British Institute of Learning Disabilities (BILD)
www.bild.org.uk/index.html
BILD is a national charity committed to improving the quality of life of people with a learning disability. They do this by influencing policy makers and other decision makers, encouraging good practice among practitioners and helping people with a learning disability to take charge of their own lives and become part of an inclusive society. BILD have a black and minority ethnic community Project Officer who runs the Personal Advocacy Story Telling (PAST) project, gathering stories regarding good practice in advocacy and the personalisation agenda. To find out more about the PAST project, visit **www.bild.org.uk/humanrights_past.htm**.

Ethnicity Training Network
www.etn.leeds.ac.uk
The Ethnicity Training Network was set up with funding from the Department of Health and is based at the Institute for Health Sciences and Public Health Research at the University of Leeds. The Network provides training in ethnicity, diversity and health care, and their website has an extensive resources section.

Resources 2

Mencap
www.mencap.org.uk
Mencap is a national organisation working with people with a learning disability to change laws and services, challenge prejudice and directly support thousands of people to live their lives as they choose. They have an excellent website providing a comprehensive range of information and resources. In particular, there is a link to the *Reaching Out* report (**www.mencap.org.uk/document.asp? id=11432&audGroup=&subjectLevel2=&subjectId= &sorter=1&origin=pageType&pageType=112&page no=&searchPhrase=**) and a link to an accessible version of the report (**www.mencap.org.uk/document.asp?id=11433& audGroup=&subjectLevel2=&subjectId=&sorter= 1&origin=pageType&pageType=112&pageno= &searchPhrase=**).

Midland Mencap
www.midlandmencap.org.uk
Midland Mencap run the Reaching Out project (on which Mencap's *Reaching Out* report was based), nationally recognised as a model of good practice in engaging with black and minority ethnic communities. To obtain a copy of the report, as well as an accompanying DVD (limited copies available), call 0121 442 2944. Midland Mencap also run the Apni Marzie project, which supports Asian women over eighteen years old who have learning disabilities; in addition, they provide a range of support services.

National Advisory Group on Learning Disabilities and Ethnicity (NAGLDE)
www.learningdisabilities.org.uk/our-work/ community-and-inclusion/national-advisory- group-on-learning-disabilities-and-ethnicity/#what
NAGLDE advises government on the changes required to promote the interests of people with learning disabilities from black and minority ethnic communities. They are coordinated by the Foundation for People with Learning Disabilities and work closely with a range of national organisations to achieve their aims.

National Advocacy Network
www.advocacynetwork.org.uk
The National Advocacy Network is the only fully inclusive network for advocates and advocacy schemes across the UK.

National Learning Disabilities and Ethnicity Network (NLDEN)
www.lden.org.uk
NLDEN provides a good practice and information-sharing network on all initiatives concerned with learning disability and ethnicity.

Valuing People Now
www.valuingpeople.gov.uk/dynamic/ valuingpeople86.jsp
The ethnicity section of the Valuing People Now website has a wealth of useful information, including easyread versions of the Race Relations (Amendment) Act 2000 as well as an Ethnicity Audit Tool, which can help Learning Disability Partnership Boards and services work out how they are doing and what they can do to make things better for people with learning disabilities from black and minority ethnic communities.

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