



**Consultation on the advocacy
needs of people with learning
disabilities from BME
Communities in the Wakefield
District**

**FINAL REPORT
Produced by YOUR VOICE ADVOCACY PROJECT**

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Introduction

Wakefield Metropolitan District Council commission Cloverleaf Advocacy to provide advocacy for people with learning disabilities above the age of 18, across the Wakefield District. This includes one-to-one advocacy, self-advocacy facilitation and citizen advocacy.

Included within the contract is support to self-advocacy groups across the district for people with learning disabilities who are going through the transition process. In addition, the service provides support to Partnership Board service user representatives to fulfil their role on the Board.

The service is provided in line with the learning disabilities White Paper, '*Valuing People: A new strategy for learning disability in the 21st Century*', and more recent strategies, such as '*Valuing People Now: from progress transformation*'.

Part of the service provision is focussed on engaging with Black and Minority Ethnic communities to identify what type of advocacy services are required. Cloverleaf Advocacy has commissioned Fazeela Hafejee to lead on the project with the Your Voice Advocacy Team. The aim has been to:

- Make suggestions on the appropriate models of advocacy for this group.
- Make recommendations on improving existing advocacy services and to identify the cultural competencies required to work with the BME communities
- Identify the advocacy needs of the BME community through community engagement

Summary of the Methods Used:

- Mapping the BME population across Wakefield
- Identification of other parts of the UK where the BME population is actively accessing advocacy; providing information about good practice
- Information from participants who are BME community members with learning disabilities and their carers , which illustrates their understanding of advocacy
- Feedback from professionals who actively engage with service users who have a learning disability
- Analysis of the information gathered to illustrate issues which are specific to the Wakefield District, and identification of the significance of this for service providers

Consultation Methods

Cloverleaf Advocacy has a background of service user involvement in consultation; and consultation; hence service user involvement is paramount throughout the project. However, due to the tight time-scales associated with this project, it became difficult to involve service users at an intense level.

The project used a variety of methods of consultation in order to maximise the extent to which people with learning disabilities and their carers became involved. The short term nature of the project meant that the team needed to ensure that trusting relationships were developed quickly and appropriately.

Snowballing:

The process of snowballing commenced with the inclusion of known groups, such as local statutory and voluntary groups. This included BME service providers, community groups, and religious places of worship.

This was followed by the identification and inclusion of a wider network of groups including the possibility of new emergent groups. There was publicity for a range of discussion groups, focus groups and creative groups. These varied by location, time of day, methods and target groups.

Methods:

Due to timing issues, service users were not involved in the design of materials such as topic guides, interview guides and questionnaires. However, through non-structured means of consultation, participants were able to generate their own dimensions.

The topics included in the focus groups also covered quality of life issues. This brought out individual, psychological, social and environmental dimensions to allow a more holistic understanding of the issues which affect people's quality of life. This generated a broader understanding of what the needs may be for a person with learning disabilities from a BME community who requires access to advocacy.

We took into consideration the participants' background, normative systems, historical differences, and experiences of racism, inter-generational relationships and the area in which they reside at present. This allowed us to identify key quality of life issues which are unique to the different minority communities in Wakefield.

A key feature of our approach was to use creative consultation methods. Such methods enabled people to engage and express their views without reliance on the ability to respond to traditional consultation methods.

The methods selected delivered both the qualitative and quantitative requirements stated in the aims. A significant component of the evaluation is discursive and interactive in nature, engaging the

participants and other personnel in a developmental process as the consultation proceeded. The approach includes a substantial element of '*participative inquiry*' (ref. Peter Reason).

The approach is based in the phenomenological school of consultation in which eliciting a series of subjective perceptions enables the consultationers to develop an understanding of the participants' perspectives. The aim is to engage with exploring, describing and understanding the personal and social experiences of people with learning disabilities and their carers from BME communities and then to try to capture the meanings that the particular phenomenon of advocacy holds for them.

Focus groups were used to elicit attributes that people think are important to advocacy. Participants were free to develop new attributes and value dimensions. Focus groups enabled the consultation to discuss particular subjects and to follow the priorities and concerns of the participants with regard to the provision of advocacy. Facilitating debate and discussion in a manner that empowers participants was seen as paramount, as it gave the best opportunity for them to express their experiences, views and thoughts in a way which made the participants into the experts. Focus groups aimed to identify and explore key issues in the provision of advocacy for people with learning disabilities from BME communities and their carers.

Creative Consultancy

In addition to conventional focus groups and interviews, the facilitators used the opportunity to adopt creative consultancy methods that do not rely solely on the verbal or conceptual competency of participants. They did this to ensure that they included all participants with learning disabilities who may have limited communication. Members of the team included staff with expertise at creative methods of engagement, and who have experience of utilising these skills.

Ethical Considerations

All participants were notified about the consultation project where all elements of the consultation were fully disclosed. This included the facilitator's involvement in the consultation and the purpose of the consultation project. This was in order to gain mutual respect and confidence between the facilitators and the participants. Giving anonymity to the participants was an integral feature of consulting ethically. Therefore, all participants were notified of their rights and the protection of their anonymity and were aware that views, experiences and concerns raised would be included in the report. Participants were assured that views and experiences expressed will not impact upon access to or use of any current or future services they receive.

Through extensive knowledge and experience of working with diverse communities, Cloverleaf Advocacy was aware of the cultural sensitivity required in consultation involving with BME communities. Consultation with ethnic groups can require an extra amount of care and due diligence.

Cloverleaf Advocacy has had experience in working with minority ethnic groups for whom English is not the first language. The team was aware of the complexities of collecting data in one language and

presenting the findings in another. This can involve facilitators taking translation-related decisions that have a direct impact on the validity of the consultation and the report which follows from it. They were aware that people who speak minority languages cannot always read that language. As an organisation, we were flexible in our approach when conducting consultation with these particular communities.

Topic sensitivity was essential in this consultation, as the interviews and focus groups explored personal and confidential issues. Some participants, especially carers, may have found it emotional to discuss their personal experiences. The facilitators aimed to actively engage and listen to the respondents so as to achieve a sense of understanding. They were careful with participants' experiences and ensured that participants understood before the interview that their participation was voluntary and that they could end the interview at any point if they felt uncomfortable with it. If participants showed signs of distress they had the right to withdraw. As the respondents shared personal information, the facilitators assured participants that their responses would remain confidential, and they explained the intended use of the data they provided.

The Legislative Context:

In undertaking this consultation, Cloverleaf Advocacy implemented good practice measures at a local level. The following gives a brief overview of the legislation and good practice policy guidance at a national level:

Valuing People (White Paper 2001): The government vision for Learning Disabilities says people with learning disabilities should be part of their local community, services need to support people with learning difficulties to become more independent, services need to offer more choice and people with a learning disability should have the same rights as everyone else. The paper also says that services need to become more culturally appropriate for Black Minority Ethnic communities.

The Human Rights Act 1998: This says that everyone has a fundamental human right to freedom of thought, conscience and religion. (Article 13).

The Race Relations Act Amendment 2000: says that statutory bodies have a legal and moral duty to eliminate discrimination, provide fair access to services, and create good relations and opportunity of good for Black Minority Ethnic communities.

The Disability Discrimination Act 2006: says that statutory bodies have a legal and moral duty to eliminate discrimination, provide fair access to services, and create good relations and opportunities of good for disabled people.

Literature Review and Examples of Good Practice

This section of the report explores other relevant pieces of research and consultation and identifies good practice for the provision of advocacy for people with learning disabilities from a BME community.

An article written by Alison Bowes and Duncan Sim '*Advocacy for Black and Minority Ethnic Communities: Understandings and Expectations*' (*British Association for Social Work*). Points out that recent policy has promoted advocacy as a means of promoting social justice for many disadvantaged groups. Yet advocacy is a contested concept, and the understanding that members of disadvantaged groups themselves have of advocacy has rarely been explored. Previous consultation indicates that understanding may vary considerably. Using empirical evidence from consultation conducted in Glasgow, this paper examines the understandings and expectations of advocacy held by BME service providers and potential service users. The BME service providers believed that they were offering advocacy, and did so in the context of a marginalized position for their services. The BME community members supported the development of advocacy services, but their own marginalization was in many ways reinforced by services they were already using. They had clear ideas about appropriate advocacy services for their situation. These ideas were grounded in their current situation, and did not necessarily conform to dominant ideas about advocacy. In conclusion, the prospects for successful advocacy are assessed.

The University of Leeds undertook the following consultation: *Partnerships, Advocacy and Independence: Service Principles and the Empowerment of Minority Ethnic People* (Ghazala Mir & Andrew Nocon, University of Leeds, UK). Partnership, advocacy, independence and empowerment are key principles that underpin current policy and practice development in the field of learning disability. The extent to which these principles are helping to shape better services for people from minority ethnic communities is discussed. Empowerment implies involvement, control and the ability to make choices. This study highlights the invisibility, conflict and barriers many people with learning disabilities and their carers experience in their interactions with service providers. The need to take particular account of diverse cultural values and meanings when seeking to provide services that are appropriate to people from different ethnic and cultural backgrounds is highlighted. Findings are based on a review commissioned by the Department of Health to accompany the White Paper, *Valuing People: A New Strategy for Learning Disability for the 21st Century*.

A recent publication by BILD (January 2010) has highlighted the barriers faced by people with learning disabilities accessing health and social care services, with a focus on advocacy services. The paper considers the challenges which advocacy services must confront if they are to offer full and timely advocacy support to people from BME communities.

There are a number of organisations which have innovative and creative advocacy services for people with learning disabilities from a BME community.

Association for Real Change, (ARC) is a membership organisation, which supports providers of services to people with a learning disability to promote real change. They highlighted the following good practice services:

- **Leeds - Shakti**

The project supports people with learning difficulties from South Asian communities, who face disadvantages because of their impairment and ethnicity, to change their lives. It is run by Connect in the North. Shakti raises self-esteem, confidence, knowledge and life skills through 30 weeks' training. This covers subjects including personal rights, accessing help and managing support.

- **Dudley – The Healthy You**

This project supports people with learning disabilities and their carers from BME groups. The Learning Disability Partnership Board Ethnicity Sub-Group meets bi-monthly It has family carers and self-advocates from minority communities on the Sub- Group and Partnership Board. Dudley Ehsas Carers supports children with special needs and adults with learning disabilities. It plans a training programme for family carers in a community language. Dudley APNA Group has a part-time development worker who supports a dozen self-advocates and provides educational courses.

- **Walsall – Ethnic Advocacy Black Country**

This is a partnership between two BME advocacy groups in Walsall and Dudley.

- **Torbay**

A large day centre in Torbay has started making good links with local minority ethnic communities. Staff organised a fund-raising event with a local Indian restaurant which was very successful. This year another Indian restaurant is taking part along with an African drummer and Chinese dancers. It is planned to make this an annual event to bring the different cultures in Torbay close together.

These examples highlight the diverse range of methods and approaches that can be used to engage and consult with BME communities so that advocacy becomes an integral feature of service provision.

Models of Advocacy

One of the aims of the consultation is to identify which model or models of advocacy are the most appropriate for the BME population of Wakefield. The specification for the Your Voice Advocacy service includes reference to the following well established models of advocacy:

Representative Advocacy

This involves people speaking on behalf of an individual service user or group. They may or may not receive payment for acting as an advocate.

Self Advocacy/Collective Advocacy

This is where a group of people, sometimes from very different backgrounds, campaign on behalf of themselves or others to try and change things. This could be a national organisation or a local one focussing on either national or local issues.

Citizen Advocacy

This is where someone else speaks up on behalf of the service user or helps them to speak for themselves. It is based on the idea of a 'valued citizen' (i.e. someone who does not have a problem getting heard), working with a person who is discriminated against. The relationship may develop into friendship or they may just work together to develop the service user's skills or confidence to manage their own situation. Citizen advocates usually come from a recognised and co-coordinated scheme.

Peer Advocacy

This is where service users, who have experienced similar problems of not being listened to, may help others to speak up for themselves. A peer advocate is likely to have a very good understanding of what other service users are going through.

For the purpose of this consultation, the team did not refer to the specific titles of the models of advocacy when trying to ascertain which model would be most appropriate in meeting clients' advocacy needs. Facilitators referred to key elements of the models to gauge an understanding of what participants required, to be able to help them to identify optimal models of future service provision.

CONSULTATION ANALYSIS

In this section of the report, we analysed the quantitative and qualitative feedback received through the various methods of consultation. Paramount to this consultation was the inclusion of service users, parents and carers from BME communities. Consultation with service users and carers included individual interviews and focus groups. They wanted to gather an understanding of peoples' previous experiences of accessing health and social care services, which may have shaped their current views. It was the aim of the facilitators to explore how future advocacy services could be configured to better meet the needs of people from BME communities.

Feedback from Service Users

Service users who had already used advocacy services were accessed through the Your Voice database. Individual interviews were arranged after identifying any specific needs or requirements to support the service user appropriately during the interview. In this section of the report we detail the issues raised and the suggestions which made for future advocacy provision.

Service users were asked if English was their first language. All respondents said English was not their first language. They highlighted this as one of the major barriers to communicating with professionals when they were trying to access services. There was a general lack of confidence in speaking out and asking for services that they were entitled to. Service users spoke about it taking a '*long time*' to feel confident to do so. Some of the service users recommended that the employment of BME specialist advocacy workers would overcome language and cultural barriers. A female service user suggested that gender-specific advocates would be culturally and religiously more sensitive.

Those who had accessed advocacy services reported the experience as being beneficial in helping them to feel more in control of their own lives. One particular service user referred to the opportunity to talk through problems as being quite therapeutic.

Several service users mentioned how they preferred the one-to-one advocacy service which was provided within their own home. Service users felt they were able to build up trusting relationships with advocates easily in a familiar environment. This was a model that was accepted, and service users felt they benefitted from it.

Self Advocacy Groups

As part of the consultation, a local self-advocacy group was asked to identify what advocacy services might be able to do better from a service user's point of view, in order to engage people from BME communities. They highlighted the following key areas:

- To make information accessible
- Actively engage carers to raise awareness about advocacy and learning disability
- Take services out to the community

Feedback from Family Carers

Two focus groups were held in a local community centre setting where parents and carers felt comfortable and safe to speak openly about issues that were sensitive and confidential. Carers were contacted by a marketing exercise through local community networks. A total of 15 people attended the focus groups.

The focus group began with a welcome and introductions, and a brief explanation of the aims and objectives of the group and the over-arching aims of the consultation. This created a lively discussion about consultation – some carers were very positive about the consultation and the potential outcomes, whereas other carers felt that consultation and consultation can often lead to little or no action.

Perceptions of advocacy:

Within the focus group, the facilitators took the opportunity to explain what advocacy involved and what it could achieve for people with a learning disability. There was a common feeling within the group that carers had 'been doing advocacy themselves for years'. They were unaware of professional advocacy services which may have been able to support them. This then stimulated a discussion on how carers felt advocacy would have been useful in past situations (please see appendix 1 for full details). A summary follows:

a) A carer felt that her daughter was not able to access appropriate services for her physical health needs, and as such, attended several difficult meetings with service providers. The outcome for the person with a learning disability was ultimately positive, but the carer highlighted that additional support at the meetings for her daughter would have been beneficial. The carer also highlighted that fact that her English is of a high standard, and wondered how someone who could not communicate as well in English would have coped.

b) A carer told the group how his son's day centre closed and his son was left with no services in place. Again, the carer supported his son at a range of meetings, this time without success. The carer had accessed advocacy from another provider, which he felt did not meet expectations.

This discussion led to further debate about how other social care services were configured, in terms of their opening hours and the availability of staff. The group suggested that when future advocacy services are planned, service users should be allocated two advocates in order to cover for part-time workers, annual leave or sickness. The rationale behind this suggestion was that carers felt their sons and daughters who have learning disabilities require a longer time than usual to build up relationships of trust and to become comfortable enough to communicate.

Cultural Issues:

There was some discussion of the lack of understanding of the concept of learning disabilities amongst BME communities. A participant said she is still frequently asked, *'Is your daughter better now?'* Frustration was expressed by members about this lack of awareness, and suggestions were made that advocacy services might be able to play a pivotal role in awareness raising.

The issue of stigma attached by the community to both having a learning disability and to accessing services was raised. One participant said, *'We used to have an access bus that collected my daughter but as it was so obvious and visible I declined further service'*. She acknowledged that this was detrimental to both her as a carer, and her daughter, but felt the pressures of culture were *'too much to deal with'*.

In addition, the group suggested that advocacy services should employ staff from local BME communities. This would help them to feel comfortable about sharing their views and needs with someone who has a sound understanding of their culture and religion. A participant shared with the group about how she felt social care services lacked cultural understanding. As her daughter reached adult age, within her culture it is deemed inappropriate to have mixed sex support groups and to be escorted by men. She said *'I felt frustrated in having to explain my culture and religion all the time to people who didn't seem to care'*.

Recommendations for advocacy services:

Participants were able to express how advocacy services should be considered in the future to support them to access health and social care services. Facilitators were able to identify the following recommendations:

- Services should be culturally competent.
- Advocates from local communities
- Advocates who have multi-lingual skills
- Provision of information about services and rights and guidance
- Services that run beyond traditional office hours (9am to 5pm, Monday to Friday)
- Services that are taken to the community
- Integrated services
- Better links with existing networks
- Permanently funded specialist posts
- Clarity about service provision and professional roles and responsibilities.
- Printed information which is both in community languages and accessible.
- Developing trust with the service.

Gaps in service provision:

Several carers raised the issue that there was not an advocacy service for children (under the age of 18) as many of the carers present had sons and daughters of this age. Although the current advocacy service can signpost to support networks, individual advocacy with young people cannot take place under current commissioning arrangements.

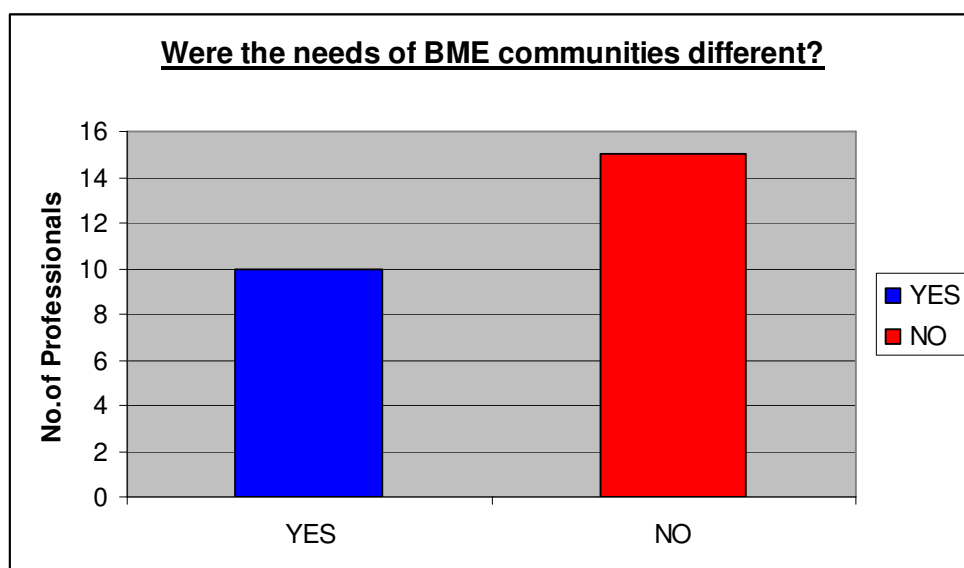
For more information on the carer's consultation see appendix 1

Feedback from professionals:

As part of the consultation process, one of the methods undertaken was to send questionnaires to professionals working with people with learning disabilities in Wakefield. 57 questionnaires were sent out and 32 were returned (over half of those sent). The questionnaire asked professionals whether they worked with any service users or carers from a BME background in their current role. 66% of professionals currently worked with service users or carers from BME communities.

A diverse range of professionals were consulted including: Community Nurses, Specialist Accommodation Officer, Social Workers, Physiotherapists, Person Centred Planning Facilitator, Occupational Therapist, Clinical Psychologist, Day Operations Manager, Senior Day Centre Officer, Advanced Occupational Therapist, Senior Community Nurse, Senior Social Worker, Team Manager Nursing, Head of Care, Person Centered Approaches Lead, Registered Manager, Care Co-ordinator, Sensory Nurse, DEA.

Facilitators were able to identify emergent themes and trends from the information collated in the questionnaires. Professionals were asked whether they felt the needs of BME services users or carers were different. The results can be seen in the chart below:



The participants, who responded 'yes' to the needs of BME services users being different, highlighted the following common areas:

- Communication
- Cultural (lack of understanding)
- Religious
- Language

Professionals felt that there was a general lack of understanding of the needs of this particular group. Hence, services were not appropriately or adequately configured to meet their needs. In instances where services were said to be culturally sensitive, there was a genuine concern that expectations may be raised which could not be met in reality. Generally, the feeling amongst some professionals was that BME service users were reluctant to access mainstream services for this reason. One professional said:

“People didn’t come forward for support as they did not understand the system and appeared not to feel help would suit their needs e.g. inadequate prayer facilities and or lack of cultural needs”

“...also some families seemed much more private and seemed not to want much involvement from social workers”

When asked specifically if professionals were faced with any language or communication difficulties when supporting service users from a BME background, 19 professionals out of the 32 said they had experienced language as a problem when engaging with this group. Participants used a variety of methods to overcome language and communication difficulties these included the use of:

- Interpreter
- Specialist BME workers
- Family members/carers
- Use of visual aids
- Internal staff members with multi-lingual skills.

Professionals highlighted an added complexity when working with this client group within the area of language and communication difficulties. Professionals said they had to make a judgment about whether the communication difficulty was a result of the service user speaking a different language, or whether it was a result of their learning disability.

Respondents were also asked to comment on their views about whether cultural differences made it difficult to engage with service users or carers from a BME background, in order to provide good quality service. Some professionals referred to a general lack of trust of services which made BME service users or carers reluctant to access services. There were references to a culture where it is seen to be a stigma to access support or services outside the immediate family. One professional suggested there was a need to learn about other cultures in order to fully engage with BME service users or carers.

Professionals referred to a two-way process that would overcome some of the highlighted barriers. They felt there was a need for constant dialogue between service providers and service users. *'Sometimes a perceived lack of understanding from both sides has created a barrier.'*

Other respondents felt this two-way process should be part of everyday working practice.

'If you are honest and act with integrity, most families will work with you. If you are generally interested in their well-being, you will empower them to enter into the open dialogue which is essential to developing a person centred plan. There is a danger that workers are so anxious about making a mistake, they end up doing nothing or avoid taking on clients from diverse backgrounds'

A strong emergent theme was the need to build up relationships of trust between service users, families, carers and the professionals. This could be achieved through a constant dialogue and open, transparent and honest approaches.

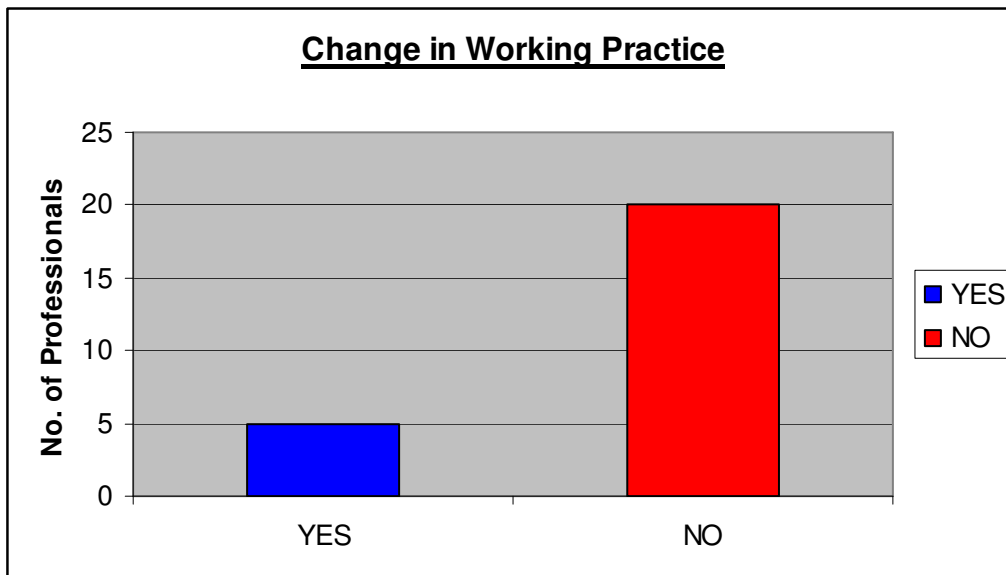
A specific example referred to on this question is Muslim service users' requirement for halal food when they use day care or residential services. Another respondent mentioned the use of alcohol in medication for Muslim service users as being inappropriate. There are differing views on the subject of alcohol in medication within Islam. This further highlights the complexity of working with service users from a different culture and religion, where there is a need to be culturally competent. However the key point is to be guided by the individual.

The views of other professionals who felt that BME services users' requirements or needs were not different their views can be summed up by the following quotation:

'Working with people with learning disabilities the service delivery is person centred, and each service user is supported in a way that meets their individual needs and requests.'

From the evidence gathered, there is a clear indication that there are a number of factors which make the needs of BME service users different. Working with service users with a learning disability is complex, and the added multi-faceted paradigms of culture and religion makes it even more challenging. The areas categorised above are concepts that require further exploration and understanding beyond this consultation.

Professionals were also asked whether, during the course of working with a service user, they had changed their working practices to enhance or better support the service user.



A number of respondents provided further information and examples to illustrate their decision about whether or not to change their working practice. One respondent who did change their working practices said the following:

"I had to think about how to ensure the service user had access to her culture and religion, as well as promote her right to choose to, or not follow, aspects of her religion. This was sometimes in opposition to the wishes of carers."

Other participants identified culture and religion as the main reasons for changing their working practices. Professionals identified a number of support mechanisms which they could use to incorporate cultural and religious differences, and which would improve the quality of support they provided to service users. These included specialist BME workers, carers, family members and interpreters. Respondents acknowledged that there may be conflict between families' wishes and views and those of the service users and they took those into consideration when seeking support or advice. One professional acknowledged that service users from BME backgrounds cannot always read or write the language that they are able to speak. In situations such as this, the worker would have to ensure that appropriate measures were put in place so the service user was aware of their rights and the services which were available to them. This may include information being provided in non-written formats.

In contrast, professionals who responded to the question by saying that they did not change their working practices highlighted that good working approaches required a person centred approach. In essence, they treated each service user as an individual who had unique needs. Thus,, the way they supported the BME service user would be the same as the way they supported the indigenous

population of service users, by providing support services which are tailored to the individual's needs. A professional stated:

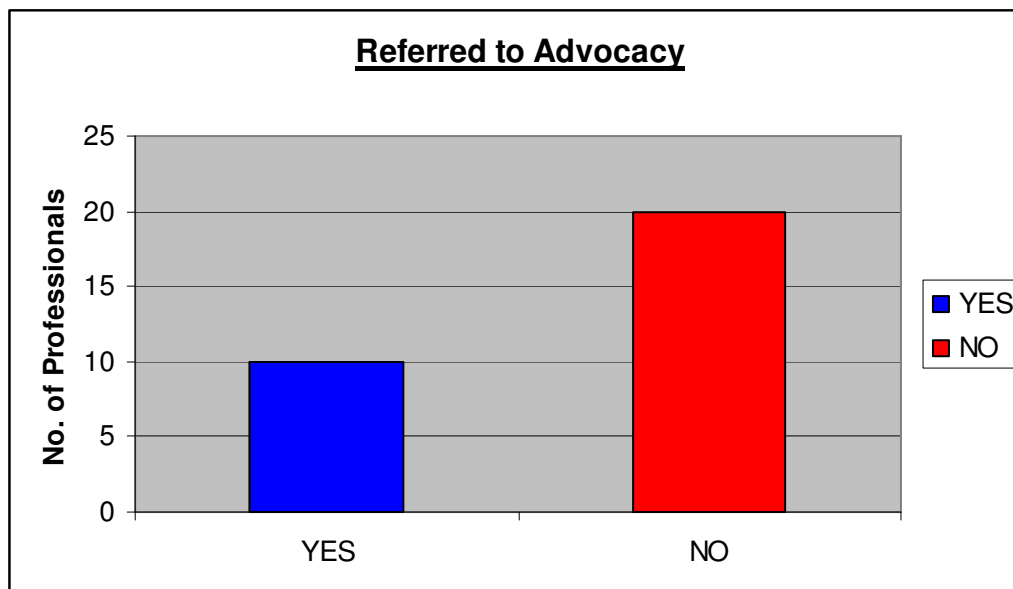
"This can be overblown – if we work in a genuinely person-centred way, then it is reasonably easy to work sensitively, by respecting the cultural needs of service users and their carers. Everyone is 'unique' and requires a individual response"

Another participant highlighted the example of using an interpreter as: *'just another method of making communication possible'*. The respondent indicated that service users of learning disability services have varying communication difficulties, and that a number of measures are adopted to ensure their needs are communicated appropriately and effectively. This was not viewed as a significant change in working practices.

The variety of views on the subject of whether professionals change their working practices indicates that it is difficult to make a substantive conclusion on this matter; this is because respondents may attach significantly different meanings to the concept of what amounts to a change in working practice. As a brief summary, what a professional may view as a change in working practice because a service user is from a BME community, another may see as working in a person-centred manner.

Referrals made by professionals to advocacy services:

As part of the consultation process, professionals were also asked if they had ever referred a service user from the BME community to the advocacy service. Only 31% of participants who completed the questionnaires had referred to the current service.



If professionals had referred to advocacy, they were then asked whether the current advocacy provision in their opinion met the need of BME service users. If respondents felt that advocacy services did not meet the needs of this particular group, they were asked to comment on how services should be configured and improved in the future. Here are some of their suggestions;

“I think having advocates from BME backgrounds could become tokenistic, if they are recruited to work with BME service users only. Existing advocates need to develop more confidence in working with BME communities. Existing advocates are doing a good job anyway.”

“Whilst shared language and culture are obviously essential, it is important that advocacy services deliver results. Did it achieve the outcomes which benefitted service users, and carers hoped for?”

There was an emerging debate amongst professionals about whether the use of advocates from BME communities could be a potential solution to a lack of understanding of cultural and religious needs. Others felt that this was an inappropriate solution as it created segregation within the whole community. They felt a holistic approach to providing culturally competent services which are delivered by all staff would be a more effective solution.

This perception is supported by the recent BILD report, which states: “Advocacy services, however, can place so much emphasis on the need for BME advocates that this can be seen as a quick fix to the “minority issue” and, at the same time, majority community advocates can feel disenfranchised from working with BME clients. The contribution of BME advocates should be seen as part of the process of becoming more culturally competent, rather than an end in itself (*ibid.*). Undoubtedly BME advocates are an invaluable resource and advocacy groups should strive to have a staff team reflecting the cultural and ethnic diversity of the clients they serve.”

Emergent Themes from consultation with professionals:

Person Centred Practice:

Some professional's staff felt it was unnecessary to change their working practice in order to be more sensitive to differences in culture or religion for those service users from a BME background, because the ethos of the organisation is to provide services that are tailored to individual needs; this meets the requirements of service users regardless of ethnicity. For example, acknowledgment of religious festivals was incorporated into service delivery and each religious festival was celebrated in a way that was appropriate to that religion. The staff felt *"being aware of the culture and diversity was key to providing an inclusive service."*

Cultural Differences:

Professionals were acutely aware that although the BME community within Wakefield were predominately from South Asian communities and were Muslims, that there was diversity within this community and also that there were new and emerging communities which would be accessing services in the near future. Hence, they had to be proactive in ensuring their services were flexible and diverse enough to meet the needs of various communities.

The Stigma Attached to Having a Learning Disability within the BME Community:

Professionals highlighted that there was a stigma attached to having a learning disability within this particular community. This meant there was a reluctance to ask for support and help when needed. There was a general culture of *'caring for your own'*, which often resulted in families only asking for support when they were at crisis point. An example was given of when a service user was supported to access a non-learning disability-specific BME women's group. During the session, the group members did not engage with the service user and she wasn't welcomed into the group. Staff at Day Opportunities felt that more awareness needs to be raised within the local communities about learning disabilities so that the stigma can be overcome. In essence, this would lead to improved access to services.

Communication – Use of Interpreters or Family Members:

Communication was raised as an issue, especially for those carers for whom English was not a first language. This made it difficult for service users or carers to engage with services users. Interpreters were commonly sought to help with communication. However, it was felt families preferred to use younger members of their family to act as interpreters. An example provided was what happened when correspondence which required a response was sent to family home, written in English. Often families were unable to do this, In order to overcome this type of problem, services would use other methods of communication, such as the telephone.

Perspectives of BME Specialist Workers:

As part of the consultation, facilitators carried out six individual interviews with specialist BME workers within the Wakefield District. The consultation concentrated on their experiences of working with the local community but also aimed to identify what sort of advocacy service provision would be most appropriate for this particular group.

Experiences of accessing services shaped future expectations. BME workers shared the view of service users and carers that service users had often received a good quality service as children. This had raised expectations about the transition to adult services. However, often services have not met their needs. There is a genuine fear that if a complaint is made against a member of staff or a service that this will result in withdrawal of services or have a negative impact on the service they were offered.

BME workers highlighted the difficulty they faced in engaging with the local community, which is deemed as being *'very closely knit'*. Although they may be from the same background, community members would initially approach them with suspicion. They also discovered that there are historical differences within the community which are complex to understand if you are not a part of this community.

Feedback from Advocacy Workers:

A part of the consultation was to speak with existing advocacy staff in the Wakefield District and to seek their views on how the advocacy provision of which they are a part, can be improved or configured to meet the needs of service users from a BME background. Several common themes emerged from these discussions.

A common theme that arose from advocacy staff was that a lot of BME specific training which advocates have attended has predominately been focused on Muslim communities and their religious needs, rather than concentrating on the needs of people with learning disabilities from this community. Advocates are eager to receive specific training to broaden their knowledge on relevant BME issues which will support them in their future casework. In essence, this would result in the service gaining more experience about engaging with the BME community.

Participants shared previous experiences of trying to engage with BME communities through identifying community leaders, and which had not produced the outcomes they hoped for. However, they were not disillusioned, and still viewed this an effective model of engaging with the community.

There was a degree of uncertainty regarding the role of the BME involvement worker in Wakefield. It was felt that this role seems to be the obvious link for the advocacy service to use to engage with the BME community in Wakefield. It was voiced that to a certain extent, this post should be pivotal to putting service users and carers in touch with advocacy services and bridging existing gaps caused by lack of engagement.

All participants spoke of advocacy services doing more in terms of raising awareness of the current service. It was felt that establishing a presence within BME communities through using drop-in sessions or informal information sharing was essential to raising awareness and becoming known to the BME community. Another way this could be achieved was through creating accessible leaflets, detailing the service and what expectations people could have of using the current advocacy services.

There was a general consensus that the current advocacy service isn't necessarily *'getting it wrong'* in terms of engaging with the BME community but a feeling that the service could do more. The issue of resources was raised as a potential barrier to fully engaging with the BME community. Staff felt there is currently little time available within the project to dedicate to the engaging with BME communities. More resources would be required for a robust plan of action to be implemented.

There was a definite frustration amongst some staff members that little is being done locally and nationally to engage with this service user group. There was also a feeling that a change in contextual culture rather than specific advocacy practice may be the solution to achieving outcomes which engage people in advocacy services.

Summary of Findings

The consultation analysis enabled the consultants to identify themes and trends from the experiences of service users, carers and professionals. This enabled them to make recommendations for the configuration of future advocacy services. Although some participants had not accessed advocacy services, their general experience of accessing health and social care services shaped their views about how future advocacy services could meet their needs.

It was evident from the consultation that communication was one of the biggest barriers identified in engaging service users and carers from BME communities. It was felt that generally it is difficult to engage people with a learning disability. This was further complicated by English being a second language for some service users. Whilst services used interpreters to overcome communication and language difficulties, many service users and carers felt that this was an inappropriate mechanism. Service users and carers suggested it would be preferable to have BME specialist advocates to ensure their views are represented rather than using a third party, where there is the fear that views can be misinterpreted or lost in the interpreting process.

It was identified that existing health and social care services did not meet the needs of BME communities in terms of culture and religion. It was felt that staff needed further training and more resources should be allocated to employ specialist workers who may have a better understanding. Participants highlighted the general lack of understanding of the concept of learning disabilities amongst the community and the stigma attached to accessing services, which is perceived to go against the culture of '*looking after your own*'. This highlighted the issue that it may be difficult to offer services which are culturally appropriate at this stage, when a lot more intensive work needs to be undertaken with the community about raising awareness of learning disability issues. There also needs to be work on the whole culture of stigma about accessing services. In order to move towards an ideal service provision for BME communities, it is evident from this report that a two-way communication between service users, carers and service providers is essential so that trust can develop and truly person centred services can be provided.

There was a general feeling amongst participants that there was a lack of awareness regarding services that are available for providing information, advice and guidance, including advocacy. It was evident from the professionals who were consulted that there is a lot of good practice work in terms of trying to engage BME communities across Wakefield. However, it is felt that a cohesive strategic approach involving a range of services would be beneficial.

Recommendations

In the initial part of the report, facilitators were able to identify various types and methods of advocacy. During the consultation, consultants were able to distinguish particular attributes to the models of advocacy to ascertain the most appropriate for the needs of BME communities

Participants valued the one-to-one, face-to-face contact from advocates. Services offering home visits or meetings in places of the service user's choice were valued. This enabled service users to feel safe and comfortable so they could discuss matters of a personal and confidential nature. Service users and carers appreciated one-to-one advocacy for individual issues which required support or representation.

They also spoke about the potential benefits of group work for peer advocacy and carer support purposes, and felt that this type of work enhanced the principles and values of advocacy. The indication was that these groups would be only effective if they were community-based, in an environment familiar to the people they were aimed at. A request was also made to be able access advocacy through open drop-in sessions which are based in the community. People highlighted the need to provide a seamless service and the need to have close working relationship with other agencies.

Specific suggestions made include:

- There needs to be a strategic and cohesive direction in engaging with BME communities, which results in holistic service provision from all service providers. The aim should be to offer less fragmented and possibly seamless services.
- An emergent finding is that communication can compound the difficulties that all carers have when engaging with services, and have to negotiate and access services. Cultural and communication barriers make it complex and difficult to reach a shared understanding. The recommendation is therefore to identify a diverse range of communication methods and opportunities to build shared understanding rather than placing undue reliance on formal meetings.
- Advocacy services need to be flexible within the mainstream service, to meet the needs of service users and carers from BME communities. A key element of this should be to recruit advocates who have multi-lingual skills, to help to overcome language and communication barriers. The staff team needs to be informed by a cultural understanding, whilst appreciating that each service user is an individual and unique, and that needs will be diverse within each community – a culturally competent service.
- Funding offered to third sector service providers needs to be long-term and consistent. Posts that are funded to meet the needs of BME communities (i.e. workers with bi-lingual and multi-lingual skills to overcome language and communication difficulties) should be permanent posts.

- Advocates need to identify a diverse range of methods in order to successfully engage and communicate with service users, so that they can facilitate communication between service users, carers, service providers and the wider community.
- The advocacy service should continue to be configured so that it is able to use a number of advocacy models for use in a variety of different situations: one-to-one advocacy, group advocacy, self advocacy and peer advocacy. Paramount to effective advocacy provision is that the service should be taken to the community.
- There can be lack of understanding and education around learning disabilities within BME communities. Service users, carers and professional identified that raising awareness. Could be integral to advocacy provision.
- A strong theme within the consultation was that of the stigma attached to accessing services within the BME community. Consideration needs to be given to the sensitivity of this subject and how services may be perceived by the community. For example the appearance of and markings of access buses is a case in point. Services need to be creative and *'think outside the box'* in how they are delivered. Further thought may be given to the community itself providing the service.

Conclusion

The findings from this consultation are that received models of advocacy provision should not be imposed on local communities but should be used very flexibly and creatively to develop situation-specific forms of engagement which includes advocacy. Key to the development of that is the continuation of the dialogue between, advocacy, service providers and the local community, including people who use services, by developing the opportunities for creative engagement. More effective advocacy can become readily available both for people with learning disabilities and their carers. Part of the dialogue should also be about broader contextual issues and should not simply focus on the specifics of procedures such as Community Care Assessments and the Care Programme Approach.

Action Points for the Your Voice Project:

- Ensure availability of an advocate who can speak community languages and is from a BME community.
- Provision of additional training around working with people from BME communities (including new and emergent communities)
- Awareness of advocacy raising within BME communities, through accessing community groups, drop-in sessions etc.
- Partnership working with other agencies to raise understanding and awareness of learning disability within BME communities.
- Expansion of current citizen and peer advocacy schemes through targeted volunteer recruitment within BME community.
- Initial visits to service users to be undertaken by 2 advocates, to ensure consistency and availability in case of leave/sickness etc.
- Development of existing links with carers groups to promote advocacy and ease of access and referral.
- Look into developing accessible resources for people from BME communities about advocacy.
- Develop a 'real' presence within BME community in order to build trust in the service.

Appendices

BME Consultation

Carers Group – Feedback

19.11.09

1 – Introduction to the day and each other

An introduction to the meeting was facilitated by Scott Williams with interpretation support from Mrs Ashrafi who communicated with the group members. An explanation of what the consultation was about was given and desired outcomes were discussed. There were six family carers at the meeting including Mrs Ashrafi.

2 – Feedback and summary of the report

Feedback was given to the family carers regarding the original consultation they were involved in and also findings of the report. Particular carers had issues with how the last consultation was undertaken, we decided not to dwell too much on this and progress forward with the current consultation. (Peoples opinions were feedback at an earlier meeting resulting in this second consultation being planned.)

3 - Advocacy – Exploration of what is meant by it / what people associate it with

None of the carers knew what advocacy was or what the project did, this was because they had never experienced advocacy first hand or had ever been informed / signposted toward the current advocacy service.

The facilitators took this opportunity to explain what advocacy was, this stimulated a discussion from which, the major feedback was that people could relate personal situations for their sons and daughters were support from an advocacy service would have been useful, one carer said they had ‘been doing advocacy themselves for years’ this seemed to be a common feeling within the group that as they didn’t know about other services they felt they had to do it alone.

Several carers raised the issue of why there was not an advocacy service for children (people under age of 18) as many of the carers present had sons and daughters with learning disabilities under the age of 18. This led to a discussion around how we as a service could currently only offer advice about services and signpost carers or their sons and daughters in the direction of support networks, but not do the actual one to one work.

Carers with younger children commented on having no support from social services at the moment and how they have received little information about what other support services were out there.

4 – Race, Ethnicity and Cultural Sensitivity

When discussing with the group about cultural sensitivity the response was dominated with one particular issue, language. The group was very keen on having an advocacy worker who could communicate with them in their own language. This was also a way of developing trust and forming more positive relationships. Several of the carers suggested having a worker from the local community who knew people and had good links with influential figures in the community they felt this would help our service to become more accepted.

There was also an issue raised about some of the carers who had wanted to learn to speak English to try and engage better with services however courses are very expensive and are often booked up months in advance.

The discussion around language led the consultation toward interpreters, many carers were not positive about the use of interpreters and their concerns were centred around the notion of 'true interpretation'. Some carers had experienced situations where they felt interpreters were imposing their opinions or values on an interpretation. This led to people not feeling as though they were being listened to and eventually feeling unsatisfied with a service they had received. This seemed to back up the point regarding the need to have an advocate who could communicate with the service users and carers directly.

Nobody to speak to the school about parents' concerns as no social worker involved, who would bridge this gap for them as this was an ongoing issue.

6 – What now, next steps

What they want from our service in the future

- Advocate who speaks their own language
- Accessible information – easy Urdu language just like easy English
- Printed information about the service
- More awareness raising of advocacy and different services
- Take advocacy to the community (this was most important)
- Somebody from BME community (advocate) available as and when people need them, as well as a drop in clinic style approach.
- To develop trust for the service, this needs to be built up over time, all the carers felt if they could trust the service they would definitely use service.

There is currently a lack of trust and understanding about services, a good example about this was respite, and nobody knew it existed. The carers felt the best way to develop trust was to have a 'real' presence within the community and at carers groups.

7 – Evaluation of the day

To be carried out at next meeting