

Engaging with Black and minority ethnic communities about the Mental Capacity Act



Acknowledgements

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Service manager

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Advocacy development officer

Foreword

The Mental Health Foundation has been working for many years on issues surrounding mental capacity – it is a critical but poorly understood area both inside and especially outside the mental health sector. Recently we published our report *Whose Decision?* which shows how much yet remains to be done if the Mental Capacity Act 2005 is to be implemented effectively right across the country. People from Black and minority ethnic groups have in the past had a particularly troubled relationship with mental health services, and services have often failed not only to meet need but also to treat people with sufficient sensitivity, dignity and respect. Given the generally welcome nature of the 2005 Act and its potential to help empower people, it is particularly important that service users and their families from a minority background benefit from best practice in its implementation.

We were heartened that SCIE and the Department of Health funded this latest research to seek views from Black and minority ethnic organisations about the implementation of the Act. This report makes some important recommendations about how to improve the implementation of the Act and how to make it work for everyone but particularly for people from a Black and minority ethnic background. It would be a great pity if we missed this opportunity to make the Act work for all sections of our society.



Dr Andrew McCulloch
Chief Executive

1. Introduction

1.1 Mental Capacity

Mental capacity – the ability to make decisions – is an issue that affects everyone. We all make decisions, big and small, everyday of our lives. Most of us are able to make these decisions for ourselves, although we may seek information, advice or support for more serious or complex decisions.

However for large numbers of people (for reasons of illness, injury or disability) their mental capacity may be affected in ways that prevents them from making certain decisions about their lives (on a temporary or permanent basis) and decisions are therefore made on their behalf. These include people with serious mental health problems, people with dementia, and people with learning disabilities.

1.2 The Mental Capacity Act

The Mental Capacity Act (MCA) received Royal Assent in 2005 and came into full effect on the 1 October 2007 (although some aspects of the Act had been implemented since the previous April). It applies to anyone who is aged 16 or over in England and Wales. The MCA is set out to protect the rights of people to make decisions, and assumes that everyone has the capacity to make decisions unless proven otherwise. The Act sets out parameters by which capacity can be assessed and those lacking capacity are supported as much as possible to make decisions.

The Act also establishes important legal procedures and safeguards for people who wish to plan ahead in case they lose capacity in the future, and for people who lack capacity and a decision needs making on their behalf.

The Act is based on five key principles:

- Every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise
- People must be supported as much as possible to make a decision before anyone concludes that they cannot make their own decision
- People have the right to make what others might regard as an unwise or eccentric decision
- Anything done for or on behalf of a person who lacks mental capacity must be done in their best interests
- Anything done for or on behalf of people without capacity should be less restrictive of their basic rights and freedoms.

During the implementation phase, the Act underwent an Equality Impact Assessment, the report of which contains a discrete assessment of the impact of the Act on race equality. It draws upon submissions made by stakeholders during the drafting of the Mental Capacity Bill and the work of the Mental Capacity implementation team. This included an event (held in May 2006) specifically for stakeholders from Black and minority ethnic communities to increase awareness of the Act, hear views on how its implementation might affect these communities and to encourage involvement and ongoing contact with the implementation programme team.

The impact assessment notes that the Act was broadly welcomed by Black and minority ethnic stakeholders and that 'no significant concerns were raised relating to any adverse impacts on Black and minority ethnic groups'¹. However, three potential issues were highlighted for the implementation of the Act and the Code of Practice:

- That assessments of capacity and determinations of best interests pay due regard to cultural influences upon a person who may lack capacity
- That training for those people working within the parameters of the Act, especially IMCAs, should properly address issues of cultural awareness and diversity
- That information about, and services provided under, the Act be provided in the most accessible ways possible to engage with the diverse groups affected.

1. Mental Capacity Implementation Programme (2007). Mental Capacity Act 2005: Equality Impact Assessment. London: Ministry of Justice (p. 22)

2. The project

We know very little about how the Act is understood amongst Black and minority ethnic communities and what efforts are being made in raising awareness about the Act and supporting communities in engaging with the Act. It is to address this gap that the Mental Health Foundation, with the support of SCIE, undertook the current research project.

2.1 Aims and Objectives

The main aims of this project were:

- To describe the extent to which Black and minority ethnic communities have been able to engage with the Act
- To identify factors that successfully promote, or are a hindrance to, engagement

The research addressed specific questions in the following areas:

- Individual/organisational awareness of the MCA
- Awareness of the MCA in the community
- Examples of immediate engagement with the provisions under the MCA
- Understanding of the provision of the Independent Mental Capacity Advocate
- Views on what would be useful to increase awareness of and engagement with the MCA
- Impact of culture on how the MCA is perceived and used
- Engaging with the IMCA service – challenges and possibilities
- Awareness of news/stories about the MCA in the media

2.2 Participants

The aim was to consult with representatives of 20 stakeholder organisations. Several variables were considered while selecting potential participants including:

- organisational remit - in terms of communities worked with or represented, or “groups of interest” working in a specific area, for example, the National Black and Minority Ethnic Mental Health Network
- geographical remit - whether national, regional or local. National or regional groups were more likely to have participated in policy issues while local groups may have a better understanding of reaching communities. Some of the organisations had a national remit but worked through a range of community based local organisations.
- Nature of communities – some organisations worked with established minority communities while others worked with newly emerging communities, for example, Middle Eastern communities.

Organisations were contacted through the National Black and Minority Ethnic Mental Health Network, the Catch-a-Fiya network (a survivor led network), contacts from Mental Health Foundation, database forwarded from the Office of the Public Guardian, newsletters of voluntary sector organisations working with older people and learning disability, advocacy networks, internet search and word of mouth. Please see Appendix E for the full list of organisations who participated.

Upon initial contact with many organisations it became apparent that there was very little awareness of the MCA. Despite suggesting that exploring this lack might be helpful in thinking about improving modes of engagement and awareness raising, people were reluctant to participate. This in itself is a significant finding of this study, pointing to an insufficient understanding and awareness of the Act and to gaps in the efforts to increase engagement with the Act. Some organisations and individuals who responded did not feel capable to participate in the study, but were keen to know more about opportunities offering awareness raising or training around the MCA.

Interviews were conducted with representatives from thirteen organisations. These included local, regional and national organisations. Some organisations worked across all Black and minority ethnic communities while others worked with specific communities, including South Asian, Chinese, Vietnamese, Jewish, African-Caribbean, Irish, and Arab speaking communities. Eight of the thirteen organisations offered advocacy services to their clients.

2.3 Methodology

Interviews were conducted using a semi-structured interview schedule (see Appendix A for full schedule and questions). The interview schedule was developed keeping in mind the issues pertinent to race equality highlighted by the Equality Impact Assessment and to gain more information about how well the Act is understood amongst Black minority ethnic communities.

The interview explored the following topics:

- Information about the organisation, its work and services provided, communities it worked with, and the specific role of the interviewee
- The extent of awareness of the MCA - this was explored in terms of the interviewee's personal awareness, their perspectives on the awareness within the organisation, among professionals, and within the communities they worked with (including service users and carers).
- The organisation's engagement with the MCA – their role in contributing to the consultation on the MCA or any immediate experience with the MCA
- Their knowledge of efforts to increase awareness of and engagement with the MCA and their views on what would be useful in increasing awareness around the MCA
- Information or news that they may have come across in the media
- Cultural aspects. Their views on whether “culture” would have an impact on how people perceived and used the MCA – for example, cultural beliefs and values around decision making or the idea of capacity
- Challenges in engaging with the MCA from the perspectives of Black and minority ethnic communities – for example, accessing or accepting the IMCA service – and best ways of overcoming these challenges

Five interviews were conducted over the telephone and five face-to-face. The remaining three organisations filled in a questionnaire based on the interview schedule. In two cases, the organisations were represented by two individuals participating in the interview. The interviews were 40-60 minutes long. All interviews were digitally recorded and transcribed.

2.4 Consent

The project ensured that robust ethical principles were followed at all stages, participants were provided with documentation prior to participation in order to enable them to make an informed decision about consent. A document containing information about the purpose of the research, the research team, the processes of data collection, storage and analysis and issues around confidentiality was sent to all participants along with a consent form. The documents made it clear that the participant had the right and freedom to withdraw without consequence, and assured the participant of anonymity and confidentiality. Wherever participants had questions about these processes, these were clarified over the telephone or by e-mail. Signed consent forms were collected before the interviews were conducted (Please see Appendices B, C and D for information sheets and consent forms).

3. The Findings

One of the main aims of this project was to describe the extent to which Black and minority ethnic communities have been able to engage with the MCA. In order to find this out, we asked questions about the awareness of the Act within organisations and staff, and within communities; their involvement in the consultation processes; awareness about the IMCA service; and whether they had seen stories or news items about the MCA in the media.

The second aim was to identify factors that promoted or hindered engagement with the Act. The levels of engagement with the Act were explored, looking for examples where there had been engagement and exploring hindrances and barriers where there was no engagement. Participants were encouraged to think about some solutions that might increase awareness of and engagement with the Act.

3.1 Awareness of the MCA within organisations

About half of the people (46%) interviewed said that they had a 'general awareness' and understanding of the MCA. Most of them had attended training days or conferences, organised by London Development Centre or by local authorities around the UK. One organisation was engaged in providing training in MCA to all their staff. Generally, however, the awareness within organisations was often limited to advocacy workers or to people engaging with policy issues.

Others said that they had 'limited awareness' of the Act, mostly developed through reading about it because of their own personal interest. People working with mental health issues felt that most of their time had been occupied with engaging with the Mental Health Act (2007) and that this had pushed engagement with the MCA into the background.

Even among those who had a general awareness, there were "grey areas" where the implications of the Act were not fully understood. For example, there was significant confusion among some participants about the role of the Independent Mental Capacity Advocate (IMCA), especially around their independence (a perception is that they are not independent), around how capacity would be assessed, and around decision making processes.

3.2 Awareness of the MCA within communities

The overall opinion was that there was very limited awareness of the MCA within a number of communities. Participants suggested several reasons for this lack of awareness. One of the main reasons suggested was that attention to the Mental Health Act had sidelined engagement with the MCA. The Mental Health Act was perceived as having a more direct impact on Black and minority ethnic communities and service users.

"The attention and focus of the people has been around the general issue of compulsion, as dealt with in the Mental Health Act, which obviously is particularly relevant to people from Black and minority ethnic communities, so I think the awareness around the MCA has been relatively low."

Chair, national organisation

Some people felt that "capacity" is an issue that is (perhaps incorrectly) seen as not affecting people in a direct manner. There was also reluctance to engage with issues that people perceived as too sensitive – for example, issues relating to end of life. The provision for advance decisions and written statements in the Act is potentially empowering, but this would only be understood if there is a culture change in the way people think about their own future.

"How many of us have a will? Have we made sufficient provisions for the incidents that are likely in our lives? As we get to a certain age, the potential for the MCA increases; if you have mental health issues the potential increases. But people don't think in those terms."

Service manager, regional organisation

Few people could identify specific efforts to increase awareness around the MCA in the community. Most of the information available was in the form of leaflets or documents on the Department of Health website. While the leaflets imparted some limited information, representatives working with communities where language was a big issue (Vietnamese, Chinese, South Asian and Arab communities for example) said that the available information was not appropriate.

The feeling was that issues like "decision making" and "capacity" were too abstract, and the law too complicated, for people to engage with. Providing leaflets with information about the Act was not enough, it was felt. What was needed was to make it an integral part of all service information that organisations provide.

"I think until service providers have got their heads around how to make it a practical part of what we already do in terms of informing service users then it won't become a reality for them or it will take much longer. I don't think it can be done in isolation, I don't think it is something that you go to a one day conference about. It's got to become part of the information that we work with every day; that we explain to people every day."

Service manager, regional organisation

There was consensus that levels of awareness of the Act need to be higher and that there was a lot of work to do to increase awareness around the MCA. As the use of the Act increases, a lot more questions will come up that will need to be explained to a lay person. The hope was that levels of awareness about the Act among professionals, carers, service users and communities as a whole would increase with time.

3.3 Involvement in the consultation process for the MCA

Twenty-three percent (or about a quarter) of organisations had taken part in the consultation process of the MCA. One had commented on the draft Code of Practice. One participant expressed dissatisfaction with the consultation process, where they had canvassed opinions from over forty organisations about how to disseminate information about the Act and increase awareness. This was fed back to the government but there was no further involvement in decision-making or in taking forward the recommendations.

“They tick their box that we did this consultation with a South Asian organisation. How much does that cover? After that consultation nothing happened.”

Mental health manager, national organisation

Another participant working for a national organisation said that, while the Black and minority ethnic specific department was not involved in the consultation, there was indirect involvement through the organisation’s policy officer.

3.4 Awareness of the IMCA service

The provision of the Independent Mental Capacity Advocate (IMCA) service under the MCA was found to be causing confusion both within communities and among staff. There were questions about their specific role. Some understood the IMCA as having a decision making role while others were unclear as to what criteria the decision maker would use to accept or reject the recommendations of the IMCA. The view of the IMCA as an “outsider,” provided by organisations that did not necessarily have roots in the community, caused concern about their independence in real terms and how loyal they might be to the service user.

“What is an IMCA? Who are they? What is their background? People might be scared that this is an individual coming and taking my powers away from me.”

Care coordinator, national organisation

Due to their relative isolation, language barriers and limited access to services, some communities were predominantly dependent on services delivered by organisations within their own communities. This, some participants felt, was because there was a sense of security that community based organisations had been able to provide.

"Many of the service users that I see as part of my role do not have families here. With the language barrier, they also have no power to represent themselves. Therefore, when they need people to help, they search within the community to see if there are any relevant services."

Advocacy worker, national organisation

The feeling was that the relative newness of the IMCA services, often provided by organisations with no proven links within communities, could be a problem in terms of inducing confidence and comfort among service users and families. Added to this was the fact that efforts to raise awareness were focused on staff and not the lay public.

"There appears to me remaining confusion about what IMCAs can do, particularly in relation to abuse issues and care reviews. IMCA services also appear to differ widely with some engaging with hundreds of referrals and others much lower numbers. Awareness of the IMCA in general public and communities remains poor as awareness raising and training has primarily focused on staff."

Advocacy project coordinator, national organisation

3.5 The MCA in the media

Only 15% of participants said that they had seen stories in the media covering issues related to the MCA. Again, the fact that the Mental Health Act and the MCA went through the parliamentary process during overlapping time periods was seen as one of the main reasons why there was little engagement with the MCA in the media.

3.6 Immediate engagement with the MCA

Twenty-three per cent of organisations had some direct experience in engaging with the provisions of the Act. One participant, representing an organisation working with older people, cited the following example:

"Our volunteer advocates have done some great work in enabling older people to be part of the 'smaller decisions' covered by the remit of the MCA. For example, a care home had been restricting a lady having tea and coffee against her previous wishes. After some work from an advocate, including referring the decision maker to the principle of 'least restriction' and taking into account known preferences, the lady is now drinking tea and coffee happily again."

Advocacy project coordinator, national organisation

This participant felt that the MCA gave advocates the power to ensure that older people received the right services, had real choices in decisions and had their wishes acknowledged and featured in care planning.

Another participant felt that the Act gave some protection to the staff as well, especially when there was a conflict between the wishes of the service user and of their carer.

“Sometimes carers demand that we do things but the service user has a choice. So when people are asking staff to do things to their relative – you must wash them this way, you must do this, you must do that, and the service user is saying no, the staff can then say that there is this Act that decides capacity. It doesn’t go down terribly well.”

Service manager, national organisation

Another participant talked about a case in progress where a service user with a history of short term memory loss has been referred for a capacity assessment as he wanted to give Power of Attorney to his carers following past issues of financial abuse.

There was a poignant example where an elderly person refused to be moved into hospital. The staff felt that she needed to be in the hospital and that they were failing in their duty to care for her but were unable to persuade her to move. Her view was that she wanted to stay at home. When an ambulance was called she refused to go to the hospital. She was assessed by a psycho-geriatrician who found that she had the capacity to make decisions. The staff then had to explore ways of caring for her as best as they could in her own home. The lesson for the organisation, it was felt, was that the MCA allowed staff to explore different ways of caring and respecting the wishes of the service user, even when they feel that the client could be better cared for in the hospital.

3.7 Engagement with the MCA: The Problems

The MCA was generally seen as a positive piece of legislation which had the potential of safeguarding the rights of vulnerable people. However, participants identified several factors that potentially affected how communities and individuals engaged with the Act. These factors can broadly be seen in three contexts:

- Cultural issues, including taboos around ideas of capacity, end of life issues, and mental health in general; the role of the family in a person’s care; religious requirements around care etc
- Continuing problems with access to and appropriateness of health and social care services, including reported negative experiences from Black and minority ethnic communities
- The context of setting up IMCA services, including some of the processes, and perceptions around how the Act reconfigures advocacy

3.8 Cultural factors

One participant felt that the Act had no cultural implications that would be specific to Black and minority ethnic communities. Engagement with the Act, it was felt, would depend on an individual person's relationship with his/her family, carers, and services. Others felt that culture would have a significant impact on how people engaged with the Act. The Act dealt with issues that were sensitive and, in some cultures, taboo subjects. Mental health, financial matters etc are seen as private matters in some communities and not to be disclosed to strangers. Participants who worked with clients explained the sensitive nature of this relationship.

"When I start helping them to do a letter of translation or fill a form, I have to be very careful. For example, when you are filling in benefit forms, I say, if you don't mind I have to ask you this, not because I'm curious or nosy but because the form asks you this, and if you want you can go home and fill this, I don't need to see etc. You have to be especially careful even in situations like this."

Support worker, national organisation

Advocates working within communities over a long period of time have developed ways in which to work along with these taboos. They spoke of the need to build a relationship with people through working closely with them.

"It is over time once you have built this relationship with a person that you slowly begin to understand the background of their life, and you develop a relationship with them, and that is how information is fed through to us. It's not just somebody coming off the street to see you and then they spill everything."

Mental health manager, local organisation

In many cases, there were issues relating to the appropriateness of the worker in terms of age, gender etc. One participant spoke of the difficulty in building a trusting relationship between an individual who is an elder in the community and the advocacy worker who is a much younger person. Doubts were expressed as to whether such investments in building relationships would be possible within the provisions of the Act, given restrictions in time and resources.

"I went to a consultation where they were talking about the expense of the advocate, how much they would cost, how much time they would spend and what period of time, and concerns were raised about matching language, gender, religion and age and all sorts of things."

Mental health manager, national organisation

One participant gave the following example to illustrate the point:

“There was a woman from Rwanda who was on a ward. She had a specified need for an interpreter who was a woman from the same religious background. But the interpreter who was provided was a man from a different racial and religious background and she refused to speak with him. When something is not available they give you the next best thing, which in her case turned out to be the worst thing possible given her experience of racial violence in Rwanda. That’s the way they see culture.”

Advocacy development officer, regional organisation

Another participant gave an example where a lack of knowledge about a person’s religious convictions created problems in the way people would engage with the Act. In this example, considerable distress was caused to an elderly woman in a care home by forcing her to discuss end of life issues, while her religious beliefs forbade such discussions.

The concern expressed in all the above examples was whether the new independent advocates (IMCAs) would be supported to explore cultural issues where they were relevant and work with them in an appropriate manner.

Participants were divided on their opinions on the impact of culture on processes of decision making. Some felt that in many Black and minority ethnic communities’ decisions were not made by an individual but by the family unit as a whole. Since the Act was perceived as being necessarily individualistic, these participants felt that there is potential for conflict in this situation.

“The one big thing I have found in my work is that there is no individual, it’s always the family, always a group. And the MCA or the IMCA service is about the individual. So maybe they might want the whole family to actually get together and face decision but of course that is not a provision as far as I understand. There are a lot of hierarchical issues within families so I think there would be challenges as to who could be the best person to represent the interest of the service user.”

Director, national organisation

In these situations, it was felt that the effort should be to make the whole family understand the provisions of the Act and what they need to do.

Others felt that, although not specific to Black and minority ethnic communities, decision making processes in some families may mask intrinsic hierarchies of power and the oppression of vulnerable members. One particular incident (using an example from the Mental Health Act) was cited to illustrate this:

"A wife was sectioned [under the Mental Health Act]. She hasn't got a serious mental health issue as to be sectioned but the husband had made those difficulties so huge because he doesn't get on with the wife. When she comes into the hospital the staff say she is fine. But because the husband terms her mad and paints the happenings at home in such a way that the clinicians then take his side. And she doesn't speak English so she can't represent herself."

Mental health manager, national organisation

Some participants felt that the assumption that some Black and minority ethnic communities are family oriented and that they "look after their own" creates a situation where service users are not encouraged to access information about the beneficial aspects of the legislation.

"There's an assumption in a lot of caring services that they take care of themselves. And although this might be true, it's becoming less and less true because the concept of the family is changing and people's values are changing and with that caring for the elderly or caring for people who might not have capacity is also changing. But because of this assumption within service providers, there are gaps occurring in what is offered. People don't ask for services because there isn't awareness of services, so they don't know what to ask for."

Mental health manager, national organisation

There was a feeling that care professionals, fearful of being seen as doing the wrong thing, opt for the easier option of accepting cultural stereotypes. The concern was that this would hinder people from having access to information about legal safeguards to protect their rights.

While there was no agreement about the extent of the impact of culture on decision making processes, participants agreed that careful work was needed to engage the family and carers while working with the Act. There was confusion about the level of authority and power given to the various roles contained within the Act and this was seen as a potential point of conflict.

"It would usually be the person's representative who brings up issues of cultural relevance and how these would be received in the context of the relative authority that the various people are given within the Act. I think where that might become a particular issue is around the interaction of the person's representative with the best interest assessor, even the IMCA and the authorised person."

Chair, national organisation

3.8.1 Problems with access to and appropriateness of health and social care services

There is enough evidence to show that Black and minority ethnic communities have historically been dissatisfied with health and social care services.² This dissatisfaction has extended to non-statutory advocacy services as well.³ Over the years, community based advocacy services, addressing social problems including racism, have been set up around the country, as a response to concerns about the inaccessibility and inappropriateness of mainstream services. The perception among many of the participants was that many IMCA services are provided by organisations with little or no link with communities. This, they feel, will reinforce the distrust that many Black and minority ethnic service users have based on their experiences of mainstream services.

"I think there is what I like to call a neurosis of distrust and it's a cultural thing where our people don't trust easily. They don't trust services and we know that from experience. There's a lot of kinship within communities and they probably won't envisage a time when mental health advocacy worker, independent one, would be needed in their circumstance."

Service manager, regional organisation

Some participants suggested that the process of instituting IMCA services (discussed in detail in the next section) had sidelined advocacy providers working specifically with Black and minority ethnic communities. The concern now is that the existing problems – like lack of cultural awareness, racism, lack of understanding of legal rights and policy provisions within communities, and distrust of services – would confound access to IMCA services for Black and minority ethnic communities. One participant reported that, according to the information from the IMCA provider in that locality, in over seventy referrals under the MCA in the preceding months, there was not a single referral for people from Black and minority ethnic communities.

"I don't know whether it is a cultural thing or they think that people from Black and minority ethnic communities are going to have family or friends or are going to be in communities who support them. There are Black and minority ethnic people on wards or in homes that are going to get moved around and not all of these people can have friends, relatives or someone speaking for them, so that's really confusing that there are no referrals."

Advocacy development officer, regional organisation

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2. Healthcare Commission and Department of Health (2008). Report on self reported experience of patients from black and minority ethnic groups. London: Dept of Health; NIMHE (2004). Inside Outside: Improving Mental Health Services for Black and Minority Ethnic Communities in England. London: NIMHE.
 3. Rai-Atkins et al (2002). Best Practice in Mental Health: Advocacy for African, Caribbean and South Asian Communities. Bristol: Policy Press; Silvera, M. and Kapasi, R. (2004) Health advocacy for minority ethnic Londoners: Putting services on the map, London: King's Fund; Newbigging et al (2007). Mtetezi: Developing Mental Health Advocacy with African-Caribbean Men. London: SCIE.

There was concern around processes to ensure that those service users from Black and minority ethnic communities who might benefit from provisions within the Act are properly referred to IMCA services. Participants felt that there has to be systems put in place from the beginning to monitor who and how referrals were being made to IMCA services.

Some participants felt that a general, mainstream way of addressing issues of capacity and how people are referred to IMCA services may not be appropriate for service users from Black and minority ethnic communities. Specific issues relating to cultural, religious and racial backgrounds could be left out.

"For the IMCA, if they really want to help, they need initial knowledge of that particular patient, their culture and even their family background. That is very important; otherwise they can't help, to be honest. There are so many cases, for example, where people with no mental health problems have been sectioned and taken to hospital. Why? Just because workers cannot understand that [a specific ethnic community] sometimes may speak very loud and that is taken for distress. They don't understand even the way we speak!"

User advocacy coordinator, national organisation

Some participants felt that there were not enough people working within the system from Black and minority ethnic communities that are going to be key decision makers.

The Equality Impact Assessment specifies that the training for IMCAs will properly address issues of cultural awareness and diversity. Some participants felt that there was not enough evidence to show that cultural awareness training had any significant impact on service provision in other areas for people from Black and minority ethnic communities – an argument they supported referring to the latest "Count Me In" census (though this does relate to the Mental Health Act (2007) rather than the MCA). Participants felt that there has to be much more clarity about what constitutes "cultural awareness training" within the guidance around the Act.

"People will define 'cultural awareness' in different ways. Some people see it as having a representation of staff that are from the communities that they are serving. Which is one way of looking at it. Some people will view it as people receiving a service in their own home and some people will perceive it as having the cultural knowledge to provide a service, a good service to anyone regardless of their ethnicity or cultural background."

Service manager, regional organisation

3.8.2 Concerns around how IMCA services have been set up

Two key issues, both affecting existing Black and minority ethnic advocacy services, came up while discussing factors that have helped or hindered Black and minority ethnic communities in engaging with the Act. The first one was the general dissatisfaction with the way the new IMCA services had been set up. Many participants felt that there was no real consultation with community based organisations while commissioning IMCA services in localities, and that existing advocacy services had been sidelined in the process.

“Some existing advocacy services haven’t been happy with the way that IMCAs have been put in place because they [the new services] have no contact with the local area, they’ve come from outside and they were sort of given advocacy experience and training and then they got the actual IMCA service.”

Advocacy development officer, regional organisation

One participant, who represented a local advocacy organisation working with a specific Black and minority ethnic community, spoke how a national charity had claimed to have links with this particular organisation and, through it, with Black and minority ethnic communities while tendering for the work. The understanding was that a steering group with representatives from Black and minority ethnic specific advocacy groups would be set up to advise this provider. While the charity won the tender on the strength of these claims, plans to involve local Black and minority ethnic advocacy groups have not been followed up, and the local Black and minority ethnic organisations have had no say in how the IMCA services are being delivered.

Another participant said that a local advocacy organisation, with a track record of delivering advocacy services to a specific Black and minority ethnic community for over a decade, had to close shop because their funding was stopped.

“The existing small scale advocacy projects lost their funding and [this organisation] was one which was affected. The smaller organisations lost out to larger organisations.”

Policy advisor, regional organisation

Another participant echoed this experience and said that referrals did not come to them any more as they believe they are no longer seen as a bona fide provider.

Participants felt that setting up IMCA services as experienced above had two main effects: 1) having no links with local communities, the services are seen as outsiders by people, creating issues around trust and acceptance; 2) The existing local and community-specific knowledge and links nurtured through years of working with communities are not utilised – a wasted opportunity in helping people engage with a potentially positive piece of legislation.

The second key issue that was discussed in this context was around models of advocacy that would be used by IMCAs. The concern was whether these models would be sensitive to and incorporate the variety of models of advocacy that are used within different communities.

Over the years, advocacy has developed within the context of community needs and in response to identified gaps in service provision. There have been problems and benefits to models of advocacy that have emerged in this way.

"In some respects there are negatives in terms of the general quality assurance of it and monitoring. But then there are also positives, which are about the fact that it's been able to develop quite organically and be quite responsive to the variety of needs. Some advocacy becoming more, if you like, clinically driven, some being more campaigning, rights driven, different approaches depending on contexts."

Chair, national organisation

The understanding was that the IMCA advocacy role within the MCA is specific and there are limits to the range of models of advocacy that can be employed. The Act sets clear parameters around advocacy. The consequence of developing a uniform model of advocacy, some participants argued, was that alternative forms of advocacy will be pushed out as they will be seen as somehow less authoritative.

"The Act sets a context for the forms of advocacy that you can do and within that you're going to have formalisation of advocacy itself. And in all this formalisation processes, the voices and the forms of advocacy that are prevalent within particular Black and minority ethnic communities will get left out."

Advocacy development officer, regional organisation

In this sense, the concern was not only about the role of the IMCA but about the kind of advocacy that would be in use. Many participants felt that there has to be a forum or fora through which advocacy workers within Black and minority ethnic communities could influence the discussion about the formalisation of advocacy within the parameters of the Act.

"If the IMCA role and the advocacy within the Act is allowed to develop without incorporating the different approaches into it then I think communities will not engage with it and I think it will be a case of trying to fit the client into the advocacy approach rather than tailoring the approach to the needs of the patient or the client."

Chair, national organisation

3.9 Increasing awareness around the MCA – what needs to be done

Participants were asked to identify ways in which the awareness of and engagement with the MCA could be increased within communities and organisations working with communities. Several solutions were identified, although the general feeling was that there was no proper consultation forum where these solutions could be offered and discussed. Several participants hope that the present research undertaken by the Mental Health Foundation and SCIE would pave the way to opening these dialogues.

3.9.1 Care in using language and terminology

Language was one of the main issues discussed – not only in terms of individual community languages, but how language and terminology were used in information materials.

There are communities with a large proportion of people who do not speak or read English. Easy read versions of the MCA have been produced in some of the main community languages. However, the availability of translated leaflets was seen as only part of the solution. There are concepts within the Act that are not easily translatable into various languages. There was no direct way, for example, in which to translate “advocacy” into Vietnamese or “dementia” into Punjabi. How then can this information be conveyed in a meaningful way?

To discuss the issues involved, one participant cited the example of some sexual health leaflets that were produced to increase awareness within communities. These had been illustrated with naked bodies, which the local Black and minority ethnic youth groups found inappropriate for people from more traditional religious backgrounds, and hence less likely to be picked up and read. Issues relating to mental health, mental capacity, end of life etc also had cultural taboos attached to them and needed to be represented in leaflets and information material with caution. The conclusion was that having leaflets produced did not necessarily mean they were being used by communities.

“I think that just having leaflets around in different languages is not going to help people. It is about sending out individuals who can take this information out in the languages that people can understand and it is possible that when they go to a group they can speak English but there might be one or two who do not speak English as well. But the point is about communicating in a verbal, physical, present way rather than just leaflets in GP surgeries. What would be useful are surgeries where people can come and ask you questions.”

Mental health manager, national organisation

3.9.2 Fund local Black and minority ethnic organisations to run awareness programmes

There was a general feeling that Black and minority ethnic organisations were best placed to do the job of increasing awareness around the Act. With the track record of working closely with communities, they were better equipped to judge how to impart information.

"I think it should be a concerted effort by local Black and minority ethnic groups to promote it within their community. Black and minority ethnic organisations are best place[d] to serve their communities, that's the way it is. They know what works, what doesn't. What can be discussed and what can't."

Director, national organisation

While smaller organisations were better equipped to talk directly to communities, they often did not have the resources to do this work.

"We really want to promote awareness of this Act to our service users and carers because we believe this is a positive piece of legislation. But the thing is this involves money and staff availability. We have to have more funding from other larger organisations or the government."

User advocacy coordinator, national organisation

Even organisations which were part of the consultation did not have a role to play in following up with communities once the Act was in place. Participants from these organisations felt that it would have been useful to be given funding to continue the involvement with the communities they consulted with.

"What would have been nice is if [after consultation events] we had been asked to go back and if the department had given us money to maybe run workshops in particular communities trying to explain the Act to them. We did consultations around end of life care and we went to different places of worship and asked questions. We got a lot of interesting views. But it ended there – the Act is up there and people are somewhere else. There is no connection. That is what is lacking in a lot of legislation. The government need to take the legislation to the ground level so as to be able to explain to the people how this might have an impact on them. But we have all these consultations and it ends there."

Mental health manager, national organisation

3.9.3 Work in partnership with existing groups/organisations

The overall consensus was that the best way to increase awareness was to use already existing groups and train them well to understand all aspects of the Act. Community groups had the knowledge of how to impart difficult, and even controversial, information to their communities.

“It’s about educating about any service available which is almost foreign to people. For example, we find that we can give out a lot of information in luncheon clubs because people come there and they’re in a relaxed frame of mind and if you take 10 or 15 minutes to give them some information they’re very receptive to that. So use groups that already exist.”

Mental health manager, national organisation

The words and principles of the MCA need to be physically taken and delivered to communities who are least likely to access paper flyers and web based information. A dedicated programme to do this, in partnership with local community organisations, was suggested as a way forward.

3.9.4 Train Black and minority ethnic advocates to become IMCAs

Many of the participants felt that it was important to explore the possibility of training staff already working in advocacy with specific communities to take on the role of IMCAs. Several arguments were made to support this suggestion: the organisations had already made strong links within communities; they had a clearer understanding of the specific needs and issues; they were better placed to interpret and explain the implications of the Act to the clients.

One participant said that they worked with a large number of older people, many over the age of 90, who have no family or friendship networks left. The organisation was already experiencing that the need for IMCAs was more than the number of available IMCAs to work with the clients. The organisation was of the view that, given their long term work with these clients, having accredited IMCAs within the organisation was one way of dealing with the situation.

Some ethnic communities were dispersed across London boroughs and nationally. While organisations working with these communities were convinced of the need for IMCAs from their own communities, they felt that it was difficult to argue their case because of the way in which IMCAs were funded.

“There is a need for [a specific community] IMCAs. But since funding is borough-based, this would be difficult to achieve as there aren’t enough [specific community] service users within each borough. We think joint funding across boroughs for a Pan London [specific community] IMCA service is the answer – but would they consider this?”

Director, national organisation

3.9.5 Work with community development workers (CDWs)

Some participants felt that Community Development Workers (CDWs) had a role to play in increasing awareness of the Act. The new role of CDW was introduced as part of the government's action plan to deliver race equality in mental health⁴, launched in 2005, to improve the commissioning and delivery of effective mental health services to Black minority ethnic communities. CDWs have a strategic role, which is defined by four key functions as change agent (identifying gaps in services and developing innovative practice), service developer (promoting joint working), capacity builder within Black minority ethnic communities, and access facilitator to services and community resources and to overcome cultural and language barriers.⁵ In many localities, CDWs have made connections with communities and community based groups, and these existing relationships can be used to promote awareness.

3.9.6 Make aspects of the Act an integral part of other care processes

The need to join up work around the MCA with other services was emphasised by many participants. For example, advance decisions and written statements should be discussed as part of support and care planning and overall provision of services. This will allow people, both staff and service users/ carers, to gain a better understanding of the Act as part of the care planning process.

"One of the things I thought about was that some aspects of people's wishes should be incorporated in their support plans and things like advance directives should be discussed with them. This means they're gaining an understanding of it as a process. As opposed to a one off, come to a discussion, or come to a seminar about MCA. End of story. You see if it was part of the process of support planning and part of providing a service, people discuss it and then over time they become more familiar with it."

Advocacy development officer, regional organisation

3.9.7 Involve Black and minority ethnic organisations in monitoring the delivery of IMCA services

Participants emphasised the need to monitor how the IMCA service is delivered on the ground, its impact on communities, and people's experiences. One main concern in some localities, as mentioned earlier, was the low number of referrals from Black and minority ethnic communities. Evaluating how the service is provided from the outset was suggested as a way of learning how to promote engagement with the Act. Participants felt that it was important to involve Black and minority ethnic organisations in this process from the beginning.

A similar role in monitoring the models of advocacy that were used and their effectiveness in addressing the issues of service users from Black and minority ethnic communities was emphasised.

4. Department of Health (2005). Delivering Race Equality in Mental Health Care: An Action Plan for Reform Inside and Outside Services. London: Department of Health.

5. Department of Health (2004). Community Development Workers for Black and Minority Ethnic Communities: Interim Guidance. London: Department of Health.

4. Discussion

4.1 Awareness, Involvement and Engagement

Less than half of the people interviewed had an awareness of the Act and its implications, the lack of awareness was hypothesised by participants to be due to the attention the Mental Health Act 2007 had attracted overshadowing the MCA. Language and communication were also noted as having a possible effect upon awareness and engagement, that what information was available was not in an appropriate form to meet the needs of certain ethnic communities. There were indications that some organisations had felt the involvement in the consultation process to be tokenistic, that there was lack of follow up or impact of comments. The IMCA service seemed to be the one component of the Act that had made an impact in communities. However, there was confusion and some concerns about the service and its implications for local advocacy.

It is worth noting that the three points highlighted by the Equality Impact Assessment conducted in 2006 (that assessments of best interest pay due respect to cultural influences; that training properly addresses cultural awareness; that information and services be accessible) are echoed in the experiences related here. The IMCA service in particular has been highlighted here as a subject for concern, which echoes the concerns expressed in 2006.

4.2 Key Problems with Engagement

Three key factors were raised regarding problems with engagement. These were cultural issues; access and appropriateness of services; and concerns regarding advocacy.

Concerns regarding cultural issues centred on taboos various cultures may have relating to discussion of capacity, or end of life issues. There were also concerns regarding the role of the family in different cultures and religious requirements around care. These issues may have considerable impact upon services and their response to organisations and service users from Black and ethnic minority communities.

Access and appropriateness of services has long been an issue in this area, negative experiences of services and stigma have proved barriers to engagement with services. The findings of this study show a level of anxiety that these existing concerns (lack of cultural awareness, racism, distrust of services) will confound access to the provisions of the MCA and act as a barrier to Black and minority communities fully using the Act to protect and serve members of their communities.

A particular sub-set of these concerns that came across clearly in the study were concerns regarding statutory advocacy services, and particularly the IMCA service and its impact. The study found a dissatisfaction with the way the IMCA service had been set up with (it was felt) little consultation or involvement with local communities. There was also considerable concern regarding the model of advocacy used by the IMCA service. The implications here are that if the IMCA services are lacking in cultural sensitivity, or are aware and sensitive to a number of cultures, but unable to be aware and sensitive to all cultures they come into contact with then this will be a considerable obstacle to Black and minority ethnic communities using them effectively. Equally, the very model of the IMCA – that they are a ‘fair and impartial’ outsider who comes in to help at certain points when a service user most needs them, will mean that it will be difficult for IMCAs to build a long term relationships with service

users, and such relationships may be vital for some communities and service users. However, the nature of the IMCA role was always intended to be a time-specific and time-limited one, therefore the nature and source of the IMCA service may need to be carefully considered in some settings.

As mentioned above, the nature of the Act is individualistic; it protects the rights of the individual which is a laudable concept. However, in cultures and communities where the hierarchy of the family is important, where decisions about individuals can be made by those higher up the family hierarchy the individualistic nature of the Act can clash with some cultural traditions. The nature of the MCA is to provide a framework for decision-making where individuals may lack capacity to do so themselves, it also provides a 'right' for family members and carers to be consulted, therefore much of the work to be done may need to be focussed around raising awareness of these tools within Black and minority ethnic communities.

4.3 Moving forward – what can be done?

The findings revealed a number of pathways that can offer a route forward from this point. One of the first issues that can be addressed is the issue of language, not simply translating documents but also consideration of how to convey concepts in languages that may not currently provide words (e.g. advocacy, dementia) but also methods of communication. Translation of information leaflets is not always the most pro-active or effective means of communicating with a group of people.

Further practical solutions may include creating a programme of Champions, drawn from existing CSIP MCA leads or from relevant Black and minority ethnic organisations whose job and passion it will be to engage and inform communities in ways that they can best relate to about the Act and its provisions. Additionally, a further programme of training for IMCAs who may need to be more aware of culturally sensitive issues in their advocacy work, or indeed further training for service staff regarding the complex issues surrounding the MCA in various communities.

The findings revealed a general sense from participants that Black and minority ethnic organisations were well placed to do the job of raising awareness and engagement, however funding would need to be ring-fenced to support and sustain such organisations to do this. Leading on from this, the other possibility is to use and network existing groups, to facilitate partnerships between specialist knowledge community groups and other groups (for example IMCA service providers) to ensure the best use of resources. Taking this concept one step further, a solution would be to set aside money, or encourage partnerships, in order to train Black and minority ethnic advocates to become IMCAs. Alternatively, it may be that community development workers can play a larger role in increasing awareness of the Act. A final point worth considering is the further involvement of Black and minority ethnic organisations in the monitoring and delivery of MCA related provisions.

A key point, that has been raised before in other reports on the MCA (cf *Whose Decision?* 2008) is that aspects of the Act need to be incorporated as an integral part of other care processes. To include discussions about advance decisions in care planning and to make it clear at all points in service and care planning the choices made available by the provisions of the Act.

5. Key Recommendations

- Independent research and monitoring is needed of the impact of the MCA upon Black and minority ethnic communities. For example research documenting the use of the IMCA service, LPAs and Court of Protection. Once such an evidence base is established appropriate commissioning adjustments can be made.
- There is an evident need for a strategy to raise awareness amongst Black and minority ethnic communities. There is a key role for local groups and CDWs. Information needs to be made relevant to the concerns of these communities and grounded in day-to-day realities. The strategy should also reflect the diversity across Black minority ethnic groups.
- Encourage collaborative commissioning of IMCA services for Black and minority ethnic communities between local authorities, especially London Boroughs. The CSIP regional MCA leads may be able to play an important part in this.
- Review the 'cultural influences' section of the Code by involving groups and representatives from Black and minority ethnic communities. With special attention paid to the distinction between cultural influences upon assessment of capacity and cultural influences upon best interests decision-making.

6. References

1. Department of Health (2005). Delivering Race Equality in Mental Health Care: An Action Plan for Reform Inside and Outside Services. London: Department of Health.
2. Department of Health (2004). Community Development Workers for Black and Minority Ethnic Communities: Interim Guidance. London: Department of Health.
3. Healthcare Commission and Department of Health (2008). Report on self reported experience of patients from black and minority ethnic groups. London: Dept of Health; NIMHE (2004). Inside Outside: Improving Mental Health Services for Black and Minority Ethnic Communities in England. London: NIMHE.
4. Mental Capacity Implementation Programme (2007). Mental Capacity Act 2005: Equality Impact Assessment. London: Ministry of Justice (p. 22)
5. Myron, R, Gillespie, S, Swift, P, Williamson, T (2008) Whose Decision? Preparation for and Implementation of the Mental Capacity Act in statutory and non-statutory services in England and Wales. Mental Health Foundation
6. Rai-Atkins et al (2002). Best Practice in Mental Health: Advocacy for African, Caribbean and South Asian Communities. Bristol: Policy Press; Silvera, M. and Kapasi, R. (2004) Health advocacy for minority ethnic Londoners: Putting services on the map, London: King's Fund; Newbigging et al (2007). Mtezezi: Developing Mental Health Advocacy with African-Caribbean Men. London: SCIE.

7. Appendices

Appendix A – Interview Schedule

Engaging with Black & Minority Ethnic communities About the Mental Capacity Act

Information about the interviewee/organisation

1. Type of organisation and services provided
2. Communities served

Awareness of MCA (individual, organisational)

1. Are you aware of the MCA? [Prompt: what do you know about it?]
2. Do you/your organisation have any immediate experience with the MCA
[Prompt: examples of engagement]
3. Were you/your organisation part of the consultation process/impact assessment of the MCA?
[If yes, what was the nature of involvement?]

Engagement with MCA in the community

1. How much awareness about the MCA do you think there is among the communities and people you work with (like service users, carers, professionals)?
2. Do you know of any specific efforts to increase awareness of the MCA among the communities you work with? [Example, leaflets/books for carers, training on MCA]
3. What has been useful in promoting awareness/engagement? [Prompt: compare with other government policies, provisions, laws]
4. What more would you like to see being done?
5. One of the main provisions under the MCA is the services of IMCA. Are communities aware that IMCAs can help people who have no one else to represent them (like carers)?
6. Have you come across information/news/stories about the MCA in the media?

Cultural aspects

1. Do you think culture would have an impact on how the MCA is perceived and used?
[Prompt: examples relating to values, beliefs, decision making etc]
2. Do you think there could be difficulties in engaging with the MCA among BME communities?
What would some of these challenges be? [Prompt: accessing IMCA services for example]

Any other additional comment

Appendix B – Information about the research project

Engaging with Black and Minority Ethnic Communities about the Mental Capacity Act

The Mental Capacity Act (MCA) received Royal Assent in 2005 and came into full effect on the 1 October 2007. It can apply to anyone who is aged 16 or over in England and Wales. The MCA is set out to protect the rights of people to make decisions, and assumes that everyone has the capacity to make decisions unless proven otherwise. The Act sets out parameters by which capacity can be assessed and those lacking capacity are supported as much as possible to make decisions. If decisions need to be made for people lacking capacity, the Act stipulates that they are made in their best interests and are least restrictive of their basic rights and freedoms.

We know very little about how the Act is understood amongst BME communities and what efforts are going on in raising more awareness about the Act and supporting communities in engaging with the Act. An Equality Impact Assessment of the Act, undertaken by the government, highlighted three potential issues for the implementation of the Act and the Code of Practice:

- That assessments of capacity and determinations of best interest pay due regard to cultural influences upon a person who may lack capacity
- That training for those people working within the parameters of the Act, especially the Independent Mental Capacity Advocates (IMCAs), should properly address issue of cultural awareness and diversity
- That information about, and services provided under, the Act be provided in the most accessible ways possible to engage with diverse groups affected

This research project undertaken by the Mental Health Foundation hopes to find out more. The main aims of this project are:

- To describe the extent to which BME communities have been able to engage with the Act
- To identify factors that successfully promote, or are a hindrance to, engagement

We hope to do this through interviews with representatives of 20 BME groups from across the country. The interviews can be done either face-to-face or over the telephone. We can arrange interpretation services and provide information material in a preferred language if required.

Please note that we are keen to speak to people even if they are not familiar with the Act. That will help us explore what the gaps are in the engagement process.

If you need any more information about the project, please contact the researcher at the details below.

Thank you very much for your time.

Best regards,

Jayasree Kalathil
Service user researcher

Appendix C – Participant information sheet

Mental Health Foundation

Sea Containers House, 20 Upper Ground, London SE1 9QB

Engaging with Black & Minority Ethnic communities About the Mental Capacity Act

Participant Information Sheet

- We would like to invite you to take part in a research study that is currently being undertaken by the Mental Health Foundation and Foundation for People with Learning Disabilities.
- This information sheet describes how we will be carrying out individual interviews with people as part of this study. The aim of this information sheet is to provide you with enough information about why the research is being undertaken and what it will involve.
- If there are any points that are unclear to you please ask Jayasree Kalathil to explain the information sheet to you.

THANK YOU FOR READING THIS

1. Who are the researchers?

Jayasree Kalathil is a consultant commissioned by the Mental Health Foundation in London to do this study. Jayasree is a service user and works as freelance researcher in the mental health field.

Jayasree will be supervised by Dr Rowan Myron who is Associate Head of Research at the Mental Health Foundation.

2. What is the purpose of the study?

The main aims of this project are to describe the extent to which Black and Minority Ethnic (BME) communities have been able to engage with the Mental Capacity Act, and to identify factors that successfully promote, or are a hindrance to, this engagement. We are particularly interested to hear your views and experiences, based on your/your organisation's work with BME communities.

We will be conducting twenty interviews with representatives of organisations from around England and Wales.

A number of publications will be produced from the research. Participants will be able to have written summaries of findings given to them if they request these.

3. What do I have to do?

- If you are receiving this information sheet, you will already have spoken to the researcher and agreed to take part in the study.
- You will have agreed on a time and date for the interview. You will also have chosen to conduct the interview by telephone or face-to-face (in which case you will have agreed on a location).
- The researcher will go through this information sheet with you and give you the opportunity to ask questions.
- At the agreed time the researcher will ask you a series of questions. This research interview will be recorded using a digital recorder so that the researcher can concentrate on the discussion rather than having to write your views down.
- Once the research interview is over, the researcher will explain what will happen to the information you have provided and will thank you for your time. At this point you will have another chance to ask any questions you have about the study.
- Please remember that you do not have to answer any questions you do not want to. You only need to answer questions that you are comfortable with.

4. How long will the interview take?

Each interview will take between one and two hours.

5. Will my taking part in this study be kept confidential?

All information that is collected from you during the course of the research will be kept under the strictest confidence. In writing up and reporting the findings of the research, your name will not be associated with any of the information you provide or your involvement in the study.

Usually, when the Mental Health Foundation publishes reports, there will be an appendix with an acknowledgement and thanks to the organisations who took part (they are usually listed). However, if your organisation wants to remain anonymous we can do that too. At no point would we put anything in the report that could identify people.

Each interview will be assigned an anonymous code and this will be stated at the beginning of the interview recording. This code will correspond to your research participant number.

- A list of anonymous codes will be kept in locked filing cabinets separately from any paper copies of the information you have given us for this research. Only researchers from the Mental Health Foundation/Foundation for People with Learning Disabilities research team will have access to these cabinets.

- An electronic version of the anonymous code list will be kept and only the Senior Researcher will have access to this list. It will be kept on the Mental Health Foundation's secure computer, which requires a username and password to access it

Once the digital recordings have been transcribed and analysed they will be erased. Paper transcripts of the recordings will be kept locked and once these have been analysed they will be shredded. Electronic versions of the transcripts will also be kept on the Mental Health Foundation's secure computer and only the researchers analysing these will have access to them.

6. Who is organising and funding the research study?

The project is being funded by the Mental Health Foundation and Foundation for People with Learning Disabilities.

7. What if I still have concerns or questions about this study?

If you have a concern or question about any aspect of the study, please speak to Jayasree Kalathil. You will be given a copy of this information sheet and signed consent form to keep. If the researcher stops the research for any reason, the reasons will be fully explained to you.

8. What if I have a complaint about the study?

The Mental Health Foundation and The Foundation for People with Learning Disabilities are committed to providing a high standard of service. Unfortunately, despite all best intentions things can go wrong. When this occurs we need to be informed so that every effort can be made to put things right and to prevent such errors in the future.

Anyone with a complaint against the MHF should initially discuss the problem with the named senior researcher on the bottom of this sheet. The researcher will then investigate the complaint, and will try to resolve the problem(s) to the complainant's satisfaction. Complaints should also be sent in writing to this person and they will advise you on how to do this. If problems sent to the senior researcher are not resolved within a reasonable time, they should also be sent in writing to the CEO (details will be provided.) If the response from the relevant MHF staff & CEO are not felt to be satisfactory, complainants should write to the Trustees. Staff will advise and help people through this process.

Dr Jayasree Kalathil
Service user researcher

Dr Rowan Myron
Associate Head of Research
Mental Health Foundation

Appendix D – Consent form

Mental Health Foundation

Sea Containers House, 20 Upper Ground, London SE1 9QB
Telephone 0207 803 1157

INTERVIEWS

Title of the Project:

Engaging with Black & Minority Ethnic communities About the Mental Capacity Act

The name(s) of the people you'll be talking to:

Jayasree Kalathil

Participant Anonymity Number:

This number is your special code, which means we don't have to record your name and the information you give will remain anonymous (which means people won't know your name)

Please Initial Box

1. I have read this and understood the information sheet that came with it.
I have been able to ask questions of people. ☐
2. I understand that my taking part is my choice and I can say no at any time
and without having to say why. ☐
3. I give permission for the information I give to be used in
writing up the report of this study. ☐
4. I understand that the information I give will be kept confidential
(as said in the information sheet). If I decide after my participation
that I want to say no to the study or pull out of it, I know that the
information I have given will be destroyed. ☐
5. I agree to take part in the study. ☐

Name of Participant

Date

Signature

Researcher

Date

Signature

1 for participant; 1 for researcher; 1 to be kept with service notes

Appendix E – List of organisations who took part in the research

1. Council of Ethnic Minority Voluntary Sector Organisations
2. Confederation of Indian Organisations
3. The Advocacy Project
4. Al-Hasaniya Moroccan Women's Centre
5. Vietnamese Mental Health Services
6. National Black and Minority Ethnic Mental Health Network
7. Sheffield African-Caribbean Mental Health Association
8. Chinese National Healthy Living Centre
9. Black Health Agency
10. Chinese Mental Health Association
11. Age Concern
12. Jewish Care
13. Irish Welfare and Information Centre

Mental Health Foundation

Founded in 1949, the Mental Health Foundation is the leading UK charity working in mental health and learning disabilities.

We are unique in the way we work. We bring together teams that undertake research, develop services, design training, influence policy and raise public awareness within one organisation. We are keen to tackle difficult issues and try different approaches, many of them led by service users themselves. We use our findings to promote survival, recovery and prevention. We do this by working with statutory and voluntary organisations, from GP practices to primary schools. We enable them to provide better help for people with mental health problems or learning disabilities, and promote mental well-being.

We also work to influence policy, including Government at the highest levels. We use our knowledge to raise awareness and to help tackle stigma attached to mental illness and learning disabilities. We reach millions of people every year through our media work, information booklets and online services. We can only continue our work with the support of many individuals, charitable trusts and companies. If you would like to make a donation, please call us on 020 7803 1121.

Visit www.mentalhealth.org.uk for free information on a range of mental health issues for policy, professional and public audiences, and free materials to raise awareness about how people can look after their mental health.

The Mental Health Foundation

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