

Somali Advocacy Research Project

Mind in Harrow Kings Fund

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"I can see that this has taken a huge effort to interpret the data in a fair way without overstating the results. I am glad it has led to thoughtful proposals on future developments."

Mercy Jeyasingham, Consultant, Health
Care Improvement, The King's Fund, 2010

Somali Advocacy Research Project

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Executive Summary

Somali Advocacy Research

1. The Somali Advocacy Research Project was based at Mind in Harrow, funded by the Kings Fund from 2007 - 2010.
2. The borough of Harrow had around 10,000 Somali residents, who experienced deprivation and social exclusion, with high levels of unaddressed mental health.
3. Using a questionnaire, qualitative research methods were used to collect data and conduct interviews with 50 people: 17 Somali service users, 16 Somali carers, and 16 mental health service practitioners working in the borough of Harrow. The advocate was interviewed for his perspective on 6 case studies.
4. The project evaluated the advocacy process and explored whether the model of working with families was considered beneficial, by the Somali community, and by mental health professionals.
5. The project aims were to:
 - evaluate the advocacy process with Somali mental health service users, carers and health care professionals in Harrow
 - explore whether advocacy resulted in improved communication between Somali service users and mental health professionals.
 - explain the Western model of mental health services to users, and the Somali user's cultural context to mental health professionals.
6. The questionnaire results (chapters 2 to 5) provided evidence of the polarity of positive and negative responses to interventions by the advocacy service. This polarisation was also present in the advocate's perception of his own practices and those of service providers.
7. The timely interventions of the advocacy service did improve Somali users' access to mental health services.
8. The model, which involved working with families, was perceived to be beneficial, both by the Somali community, and by mental health professionals.
9. The summary recommendations below have attempted to grasp the polarisation between the advocacy service and service providers, evident in this report. They are presented to maximise benefit for the well being of Somali people as a whole, and to offer a transferable model for advocacy in general, for other migrant, refugee and asylum seeker groups. More detailed recommendations are found on page 100 onwards.
 - 9.1. Historical Tensions
Regional conflicts and tensions in a country of origin must be addressed. Advocacy services must provide enough advocate workers to ensure a balanced service, which is representative of each part of a country of origin in conflict.
 - 9.2. Gender Issues
It is extremely important to have advocates of both genders. Female advocates must be employed, so that female concerns such as mental distress due to rape; domestic violence; effects of female genital mutilation; forced marriage; honour and shame; aggression and repression; can be dealt with sensitively, by a person of the same gender.

- 9.3. Pathways to Access Mental Health Care
- a. The role of immigration and refugee status was key to patient well being. Develop culturally appropriate ways of encouraging trust between new migrants and host communities. Offer ESOL classes to users, and contact advocacy service to book health care meetings.
 - b. New migrants often have religious theories of illness causation, which exclude approaching health care professionals. Engage with communities early (in schools and youth centres) to raise awareness of symptoms and enhance pathways to access care. Undertake mental health promotion with religious and community leaders.
- 9.4. Within Mental Health Care: Effective multi-agency working
- There were concerns about multi-agency collaboration. One person, with responsibility for multi-agency co-ordination and communication, must be funded, appointed, and rigorously audited, in order to simplify communication between agencies.
- 9.5. Within Mental Health Care: Confidentiality & Communication
- a. At healthcare staff practice meetings: discuss involvement of family members in Care Plan Arrangements; raise awareness of different perceptions of 'confidentiality': individual 1:1 consultation (western model), and 1:1 plus family (African and Asian models).
 - b. Train advocacy service workers to engage sensitivity with clients, and within required boundaries of confidentiality and privacy, in order to address client fear of gossip. Ensure all advocates are familiar with policy guidelines on data protection.
- 9.6. The Role of Advocacy
- a. Ensure advocacy service continues to work with Home Office on immigration issues; housing; carer support; and support patient understanding of healthcare system and medication control.
 - b. A conflict resolution and mediation strategy must be established before any future advocacy service is set up. The role of advocates must be tightly defined to reduce duplication with key workers and floating support workers.
- 9.7. Cultural Theories of illness
- a. Raise awareness of role of faith and religion in mental health. Develop cultural competency training in different models of health, theories of illness causation, and treatment strategies. Deliver to medical and health care professionals, advocates, social workers, and religious leaders (who are often consulted first).
 - b. Diagnosis and misdiagnosis of schizophrenia: Negotiate a strategy or formula, for discussing differences of opinion, during a consultation, when advocates and psychiatrists each have different theories of illness causation, about specific cases.
- 9.8. Empowerment of the Somali Community
- Community empowerment is the most effective strategy to create sustainable change. Invite capacity building by encouraging networks of community champions and advocates.

NT interview with advocate:

Abdi Gure explains about Somali history, and why people came to Harrow. *“There has been a civil war over the last 18 years. There has been a lot of trauma and anarchy, and many people have fled from the Civil War to different parts of the world. When Somali people come to Britain, they are already traumatised. Some of them have seen their families killed in front of them. Some women have been raped. Because of this, people have a lot of scars in their mind. Coming to a new country, the dynamics of the family change. Somali society is male dominant, and here they have to adapt to a new environment and a new system. The children assimilate very easily with the new society, and many men become redundant, and this has created a lot of anxiety and depression. They don't know about their future, and this creates further trauma”.*

Regarding mental health: *“When we see our relatives or friends acting bizarrely, we believe that there are spiritual things relating to this, and we don't give a priority to medication for this and so there is no reason to contact with the health care services. It will take time for us to contact hospitals. Also, because of the stigma of mental illness, people become confined within their families. Until the situation deteriorates completely for example, maybe neighbours can see bizarre activities, or they feel there is risk from other people, and then at this stage intervention can come in. Until then, people confine themselves within the family.”*

He explains about treatment strategies: *“Within the mosque there are imams who make prayers for this, the people who suffer mental illness, but on its own, this is not enough. Also it may be that the mosque is in a different part of the town to the family and may be difficult to reach. The imam cannot be with the patient all the time. This hinders the kind of continuous spiritual import that people may expect. We have a dilemma about widespread belief is that people are not getting enough attention to heal. People confine themselves until an explosion occurs, and people are at risk. They confine themselves until a crisis occurs.”*

“When a family see that one of their relatives is talking to themselves, straightaway, they say they need to find a sheikh or a cleric, who can read Koranic versus over them. In Islamic culture, Sheikh means someone who has knowledge about the book, and the readings. These people know about specific verses and have the power to heal. They have a special reputation.”

“An imam is confined to the mosque, and his role is jurisdiction, as a judge in terms of legal entities”. So it is a religious leader, and a legal leader? “Yes, they have legal jurisdiction, and they make judgements based on the writings in the Koran, from the religious point of view. But there are other people who make legal judgements, with regard to social care. The plans have their own arbitration system.

“Within the nomadic culture in the past, they made certain agreements, and then they decide when they sit in conference how to resolve a particular issue, then they make a judgement without the involvement of the imams. Other decisions are made through the clan elders, who make judgements. They also give advice. If there is a social problem, then it is the elders who will decide. They sit together and consult, and then they make a decision.”

Part One: Background

1. Introduction

Abstract. This project was based at Mind in Harrow, funded by the Kings Fund for 3 years. Qualitative research methods were used to collect data and conduct interviews with 50 people: 17 service users, 16 carers, 16 service providers and 1 advocate. Participants included Somali users and carers, and mental health service practitioners.

The project evaluated the advocacy process with Somali mental health service users and carers in the borough of Harrow. It explored whether advocacy resulted in improved Somali access to mental health services, and improved professional interaction with Somali people. The research explored whether the model of advocacy working with families was perceived to be beneficial, both by the Somali community, and by mental health professionals.

Results from the questionnaire interviews were analysed and presented in Section Two. The advocate's perspective and six case studies are presented in Section Three. Key issues are set out in Section Four, and a series of seven recommendations are set out in Section Five.

The recommendations suggest the most appropriate strategy for the benefit of the Somali people, and offer a transferable model for advocacy, which can be used with other UK mental health service providers.

1.i. Project Aims. These were:

- To evaluate the advocacy process with Somali mental health service users, carers and health care professionals in Harrow
- To explore whether advocacy resulted in improved communication between Somali service users and mental health professionals, and led to improved satisfaction for all, and a better mental health outcome for users.
- to explain the Western model of mental health services to users, and the Somali user's cultural context to mental health professionals.

1.ii. Borough of Harrow. Mind in Harrow, an independent charity affiliated to National Mind, was granted three year funding by the Kings Fund, to offer an advocacy service to Somali refugees who had serious mental health problems, using an advocate who had the same ethnic and cultural background and language, in order to help users to better access services. Mind in Harrow's original application to the Kings Fund can be found in Appendix A.

The borough of Harrow had around 10,000 Somali residents, who experienced deprivation and social exclusion, and had high levels of unaddressed mental health. Initial research indicated that inclusion of family members in advocacy support led to improved outcomes for patients and greater mutual understanding between them and professionals. Research was conducted to explore whether the model of advocacy working with families was valid and perceived to be useful by the local Somali community, and by the mental health professionals.

This evaluation was intended to be of direct practical use to managers, clinicians and policy makers in the borough of Harrow, involved in the development and operation of service provision to new migrants. Dissemination of the findings should be of long term value to the local Somali community and to other new migrants in the borough. It should result in improved cross cultural understanding with a wide range of professionals.

1.iii. Background Literature

Mind in Harrow's direct work with refugees and asylum seekers over more than a decade, and previous research with migrant communities, confirmed the significant needs of Somali people¹². There were an estimated 10,000 Somali residents in the borough and local Refugee Community Organisations (RCOs) report that unemployment, poverty and mental ill health were much higher than in the general population³.

Some of the barriers to Somalis accessing and receiving effective mental health services were reported as: Somali non-Western concepts of mental health; stigma and shame about mental distress;⁴ language barriers; lack of understanding of the NHS and fears of its links with other government departments, notably the Home Office⁵; previous trauma and experience of exile leading to feelings of disempowerment⁶; lack of appreciation by UK mental health professionals of these issues⁷, including a blanket application of a Eurocentric medical model, perhaps leading to misdiagnosis, which was viewed by some authors as institutional racism^{8, 9}; professionals' lack of awareness of Somali culture, and of recent political struggles¹⁰.

The importance of confidentiality within the relatively small Somali community had been highlighted in research, linked to the stigma users felt was associated with mental illness¹¹. However our own work with local Somali groups, while confirming issues of stigma, offered a contrasting view to this, namely that confidentiality and privacy had different boundaries from those in UK culture. Local community leaders maintained that confidentiality was within the family, rather than with the individual. Based on preliminary discussions with mental health professionals and with members of Somali community groups working with Somalis, we envisaged tension between this model of an advocate working with the family and the traditional Western model of 1:1 work and individual confidentiality.

The Kings Fund wanted us to explore whether advocacy working with families was valid and perceived to be useful by the local Somali community.¹² We were mindful of the importance of respecting confidentiality and developing trusting working

¹ Tobert, N (2008 & 2010)

² British Medical Association (2002)

³ Wasp, D., et al (2004)

⁴ Palmer, D. and Ward, K. (2006)

⁵ Wasp, D., et al (2004)

⁶ Patel, N. in Tribe, R. and Raval, H. (2003)

⁷ Brach, C. and Fraser, I. (2000)

⁸ Fernando, S (2010)

⁹ Fernando, S. (2002).

¹⁰ Palmer and Ward, (2006)

¹¹ Palmer and Ward, (2006)

¹² Palmer & Ward, (2006)

relationships in advocacy generally, as possible dilemmas in exploring the effectiveness of this model.

The results were intended to provide the basis to develop a strategy in order to overcome barriers to access of effective mental health service delivery for migrant, refugee and asylum seeker users^{13, 14}. They were set up in response to suggestions about issues from the Somali community¹⁵. They were intended to offer a mechanism for addressing change for service users including:

- Increased understanding of mental health service provision
- Enhanced access and increased trust in mental health services
- Reduced stigma and discrimination
- Enhanced integration with service providers
- Timely interventions in time of crisis
- Improved levels of professional intervention and social support
- Increased well being due to culturally appropriate intervention, and social inclusion
- Reduced isolation due to language barrier, enhanced motivation to seek help earlier

The project was intended to benefit mental health professionals and service providers in the following ways:

- Greater uptake of services, earlier interventions (i.e. before crisis)
- Enhanced understanding of Somali cultural interpretations of mental distress, and increased awareness of cultural manifestations of symptoms of ill health^{16 17}
- Enhanced awareness of advocacy and cultural support mechanisms
- Greater inclusion of users' family members, and other cultural brokers
- Increased training to give understanding of multiple models of understanding.

The outputs of the research should be of direct practical use to managers, clinicians, commissioners and policy makers in the NHS, social and voluntary services. We hoped the recommendations would inform local and national initiatives, and offer a practical understanding of advocacy with mental healthcare services, with a model of culturally sensitive work to promote recovery^{18, 19}.

¹³ BME Health Forum 2010

¹⁴ Solle D 2009

¹⁵ NHS Bradford & UCLAN 2009, see p.21

¹⁶ Good, B.J. and Good, M.D. (1981)

¹⁷ Tobert, N (2010)

¹⁸ CSIP, RCPsych, SCIE 2007

¹⁹ Future Vision Coalition 2009

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1.2. Process Report

1.2.i. Research Themes. The research questions, identified by discussions with the advocate and with the Kings Fund, were incorporated into a questionnaire, which was designed and submitted to the Ethics committee and to the Kings Fund for comment. Adjustments were made according to their suggestions received. All results, in every section, were set out according to three groups of respondents: service users, carers, service providers. The research questions consisted of the following themes:

- A. Interviewees
 - Monitoring information about their age, gender, ethnicity, religion, fluency of English, accommodation, and occupation.
- B. Meetings
 - With sub questions on: advocate attendance, role of people at meetings, advocacy interventions, responses to advocate presence
- C. Effect of Somali Advocacy on Well Being
 - Exploring whether advocacy resulted in enhanced well being, and positive change
- D. Cultural Understandings and Values
 - A series of questions covering respondents understanding of concept of 'Family', Female Advocates, Personal Narratives, and cultural training
- E. Service Provider Questions
 - Three questions addressed to service providers only on their understanding of: Somali Cultural Values; Somali Family Models; and Somali Concepts of Privacy and Confidentiality
- F. Cultural Ways of Understanding Mental health
 - This section consisted of a series of questions to define respondents' understanding of the meaning of term 'mental health'; beliefs about illness causation (general and specific); effects of mental illness on daily life; adjustments to cope with illness. There were also questions about practitioners in Somalia, alternative practitioners in Harrow, and we invited opinions about Harrow Services
- G. Effectiveness of Somali Advocacy
 - Questions were address to explore the support respondents received from advocate; and their opinions about effectiveness

1.2.ii. Data collection methodology.

The project used qualitative ethnographic techniques to determine all stakeholders' perspectives. We identified the main elements of the project: this involved defining the evaluation question and goals, the outputs and outcomes, the terms used and their variable meanings. We listed all the stakeholders.

We gathered data, and took steps to obtain ethical clearance, and devise time schedules. We prepared questions working with Somali community members, and refined the questionnaire, which was vetted regularly by the Kings Funds. We prepared draft letters for informed consent, and arranged preliminary meetings with all stakeholders including Somali service users, carers, supporters, and health care practitioners and providers.

We collected data, and used qualitative methodology techniques: direct observation, focus group, questionnaire, and interviews. The groups we identified for data collection were: Somali service users and carers resident in the Borough of Harrow from 1990 onwards; mental healthcare practitioners currently working in the Borough of Harrow. These included psychiatrists, CPNs, social workers, doctors, nurses, and key workers.

Outputs included: ethics board submission papers, three questionnaires (for users, carers, and service providers), regular interim process reports delivered to the Steering Committee and the Kings Fund. Our intention was to provide a transferable model that could be used to support new migrants, refugees and asylum seekers. Academic publications are in process to disseminate the findings in the wider context of cross cultural work.

Face to face interviews were conducted, using a semi structured questionnaire for users, carers, and service providers. Interviews with the advocate, including six case studies, were conducted by Josie Hinton, and one exploring historic backgrounds at the start of the project was undertaken and transcribed by myself. We were aware that Somalis were a people who used oral methods of communication, and felt that a written and or posted questionnaire for users and carers would not be fit for purpose, even if it was translated. We felt that a qualitative methodology with face to face communication was a far more appropriate and effective strategy.

There were fears due to the stigma around mental health, and fears of a population who may be recent refugees, or asylum seekers. Some may have felt that any attempt at data recording was part of 'government control'. As a result of this, we needed to use the help of the advocate in most cases, in order to approach the relevant Somali users and carers. Questionnaires were considered to be the most systematic way of collecting data about Somali advocacy in Harrow.

We decided to use translators to help us collect data from the Somali users and carers. We had a selection day in April 2009, at which we chose six translators: three men and three women, who attended our two training days in May. However, two women dropped out. We then held training meetings presenting the requirements of the research, and the proposed schedule for data collection. We informed the group about the importance of anonymity and codes to mask respondent's identity.

Each topic on the questionnaire was explained and discussed. Our Services Manager Lois Elliot ensured that each translator was CRB checked. During the year we had regular meetings with the translators, to work out who would interview whom, and to give out codes to ensure anonymity of identity. The advocate's help was invaluable with working with the translators, to smooth their introduction to patients and carers. This was important as people may have been suspicious of those from their own country of origin. They were concerned about gossip, and might be worried that the taking notes down on paper might be part of a 'government' effort. The advocate had to intervene in every case for both patients and carers, in order to make appointments. We did not translate the Letters of Consent, and the Participant Information sheets into Somali. It was felt that a verbal presenting of the information was more appropriate for the Somalis who agreed to participate.

Josie Hinton and I wrote up the results of our interviews separately, and decided to keep the data separate in this report. She summarised the case studies, and transcribed and themed her interviews with the advocate.

Template Analysis. The data collection method for the template analysis took the form of four qualitative interviews with the advocate, carried out by Josie Hinton. During the interviews, she asked the advocate to describe six cases in detail; prompts were used to assist the advocate to reflect on the approaches and strategies he used in working with his clients. The six case studies were chosen by the advocate using purposive sampling; to ensure variety of context, challenges and outcomes. Each of the interviews was recorded and then transcribed.

The template analysis method was used to create a series of thematic codes to make sense of the data. The initial template was created by Josie Hinton at Mind in Harrow and then checked for completeness and possible misinterpretations by the project team; Abdi Gure, the advocate; and Mark Gillham, chief executive at Mind in Harrow. The template was refined several times to make sure that no major themes were missed. Once the first draft of the write-up was created, the advocate checked the quotations cited and ensured that the quotations reflected the meaning with which they were said.

1.2.iii. Choice of Sample. I originally suggested we interview 20 service users, 20 carers, and 20 service providers. This proved difficult to sustain, in each category. The sample size was too large, given the resources at our disposal, the time constraints, and the availability of respondents. In the event, after discussion, we chose to stop the data collection at 16 per category.

There were concerns over respondent selection, participation, and their anonymity. At first I tried to use a more scientific methods to select every third person in the sample, but this was not possible with the service users, as some days they didn't feel well, and didn't want to engage in an interview. With carers, we interviewed those who were willing on the day. The sampling was ad hoc, and we used the snowballing technique, based on the suggestions of the advocate.

With regard to mental health care providers in Harrow, as well as contacting those mentioned by the advocate, other providers were listed and their contact details noted. Staff managers were phoned to tell them about the project, and to ask them to mention the project at staff meetings. A poster was sent around to all managers of CNWL clinics and rehab houses, inviting those who had worked with Somali patients and the advocate, to participate in the research. These were followed up with phone calls. Also the Equalities and Diversity Co-ordinator at CNWL uploaded the poster, and also added it as a news item on the front page of CNWL intranet, saying - '*Have you ever used Harrow Somali Advocacy Service*'. I subsequently interviewed participants who responded to this invitation.

1.2.iv. Concerns around Data Collection. Our concerns around data collection have been set out below. Recommendations for addressing them are provided in Chapters 8 and 9 of this report.

Bias: The project experienced challenges to complete the questionnaires with Somali patients and carers, in part because they were less likely to trust someone this did not know. Some patients were not well enough to participate. The advocate chose the service users to respond to the questionnaire, the carers, and selected a number of the service providers as well. He selected the translators we used, and rejected others. In some cases he was present in the room when the translators

were conducting the research with users and carers. The number of cases in which he was in the room is not available, but this may also have added to data bias. One service provider, when interviewed, commented: *'The project undermines the scientific validity, by the subject choosing which people to interview. This introduces a significant bias.'*

The advocate was very insistent that I remove one of the questions from the questionnaire about clan and lineage. However, we found that this question was important to retain, as another service provider commented during interview: *'There is a bias towards people of one part of the country of Somalia, and not the others'*.

Male female ratio: There was a propensity for two thirds male respondents, and one third female, amongst users, carers, and providers. We tried to address this during data collection, in order to have equal numbers, but we were still left with an unequal ratio across the board. This would be something to consider if research was ever taken again. Also three of the translators were men, and there was only one female translator. One service provider commented: *'There is an under estimation of the importance of Somali interpreters, especially female interpreters. We need mixed gender in that that role, and for interpreters'*. There was also concern expressed about female patients, as one service provider said: *'there is a bias and an undermining of female patients. The judging of the services of mental health here is also biased.'* Another said: *'Somali Advocacy is almost useless for women.'*

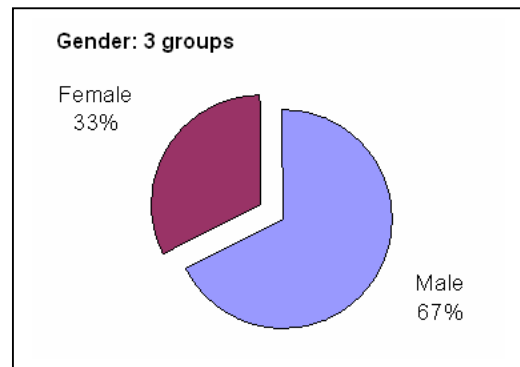
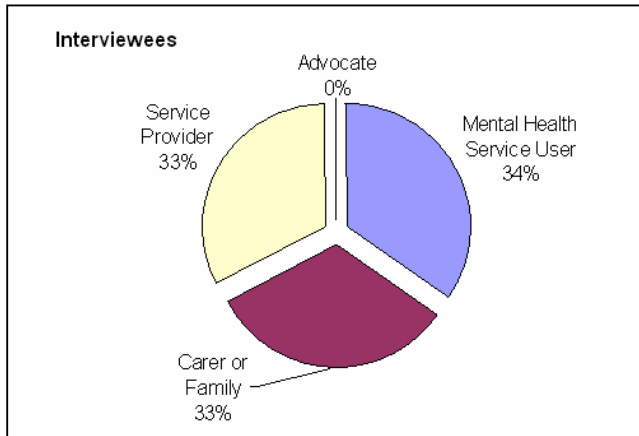
Time constraints: It took 18 months to get the project through three Ethics Boards. It was eventually passed by Brent Ethics Board, after being rejected twice in Harrow. It was very difficult to conduct all the research, within the remaining time, and with the constraints on working one day a week, even with the support of four translators from the Somali community. In the event, the CEO at Mind in Harrow brought in three additional members of staff to collect the data (Geeta Kapoor), do additional interviews with the advocate (Josie Hinton), and to check the data and prepare it for analysis (Camilla Zafia).

Named respondents: There was a problem with named respondents, who could not be connected to the advocate's database, not remembered by him, nor by any of the translators. There were additional problems, as family names in the database, were spelt in different ways, at different times. When people signed letters of consent, they called themselves something different from that held on the database, and it was difficult to tie up the spellings or even the names themselves. Three of us reviewed all the data with each of the translators and the advocate, and managed to confirm the identity of 8 named respondents. There was a problem accessing names and telephone numbers of respondents from the advocate, who kept these very private. The full list of codes and named people was kept in a locked cabinet, and the project data adhered to protocols set out by the Ethics Committee.

Somali Interim Report 2010 Presentation of Questionnaire Data

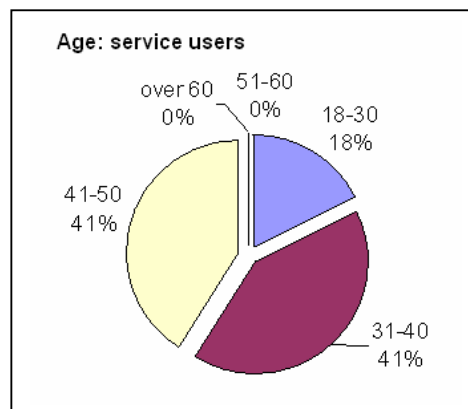
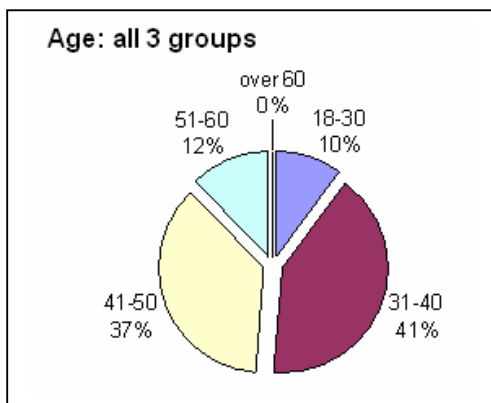
2. Interviewees

2.i. Gender and Age. We interviewed a total of 50 people, including the advocate himself, 17 service users, 16 carers, and 16 service providers. Out of the 50 interviewees, 67% were men and 33% were women.



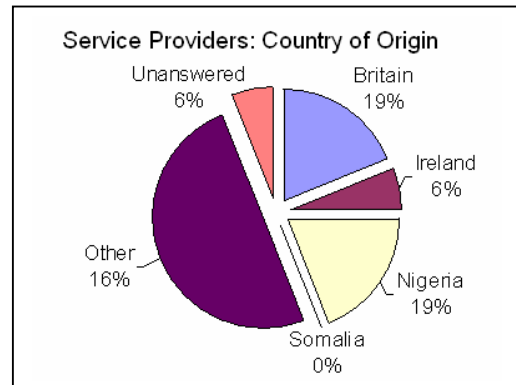
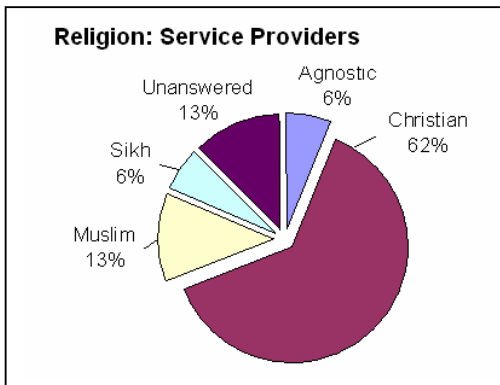
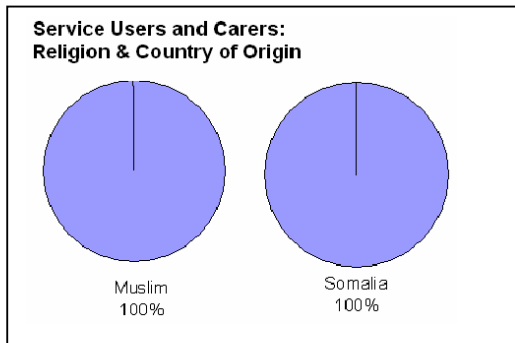
Of the 17 service users, 11 were male and six were female. The majority, 71%, said they were outpatients, 18% said they were in patients and 12% did not answer the question. The majority of them, 35%, said they had begun to use the services up to two years ago, a quarter of them said they used the service, beginning three or four years ago. Only 12% said they had been service users, starting from between five and eight years ago, and a quarter used the service over nine years ago. Only one person did not answer this question

Of the carers 11 were male and five were female. The same proportion was with the service providers, with 11 men interviewed and five women.



2.ii. Age. The carer's ages ranged from 18 to 60. The majority, 44%, were aged between 31 and 40, a quarter were aged between 41 and 50, and another quarter, between 51 and 60. Only 6% were aged between 18 and 30. In contrast, 18% of service users were aged between 18 and 30, and 41% were between 31 to 40, and another 41% were aged between 41 and 50 years old. The majority of the service

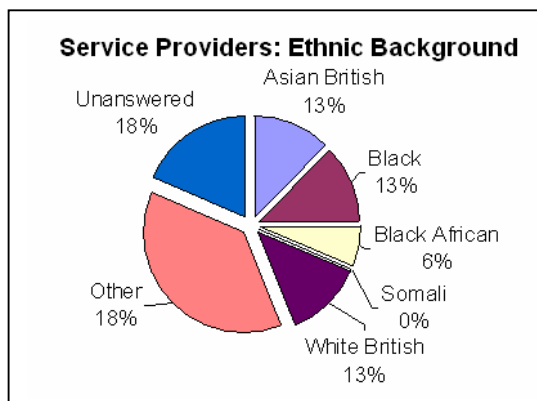
providers, 44%, were aged between 41 and 50, 38% were aged between 31 and 40, 13% between 51 and 60, and 6% were between 18 to 30 years old.



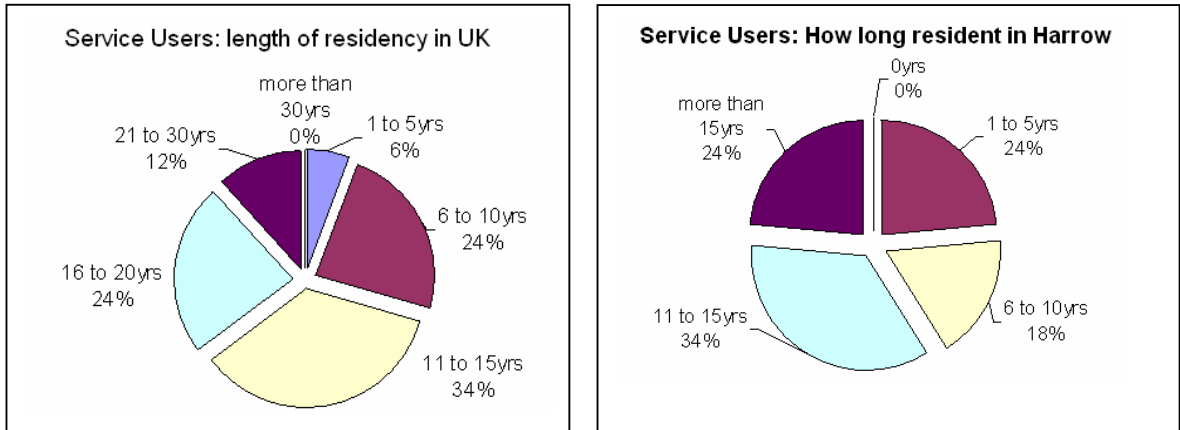
2.iii. Religion and family country of origin. The service users and their carers were 100% Muslim, and all were from Somalia. With the service providers, there were a range of religions, with the majority 63%, Christian, while 13% were Muslim, 6% were Sikh, and another 6% were agnostic. A total of 13% of respondents did not answer the question about religion.

The service providers answered the question about their family's country of origin: 19% came from Nigeria, and another 19% from Britain, with 6% from Ireland. There were 50%, who came from other countries, which included Greek Cyprus, Iraq, Kenya, New Zealand, Zimbabwe, and Rwanda.

2.iv. Ethnicity. The service users who answered the question about ethnicity, 41% said they were Somali, 12% said they were black African and 6% said they were black. 35% did not answer the question. The carers, 56% said they were black African or Somali, and 31% did not answer the question.

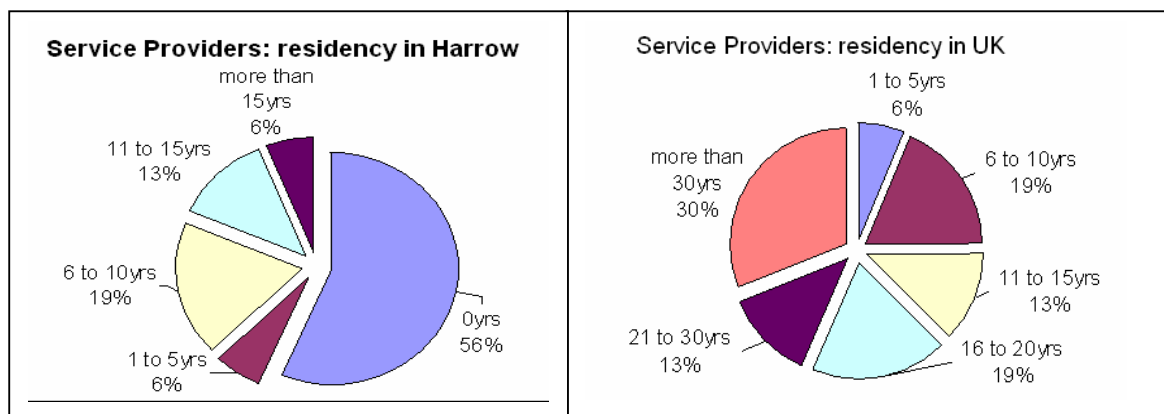


On the question of ethnic background, 13% of service providers said they were Asian British, 13% said they were black, 6% said they were black African, and 13% said they were white British. 19% did not answer the question, and 38% said they were 'other', one of whom was Chinese.



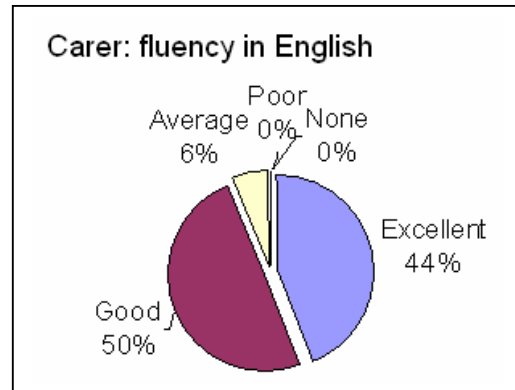
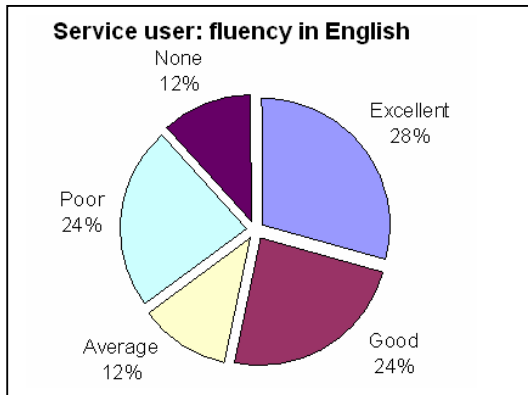
2.v. Residency. We asked how many years the service users had been living in Harrow: 24% said between one and five years, 18% said between six and 10 years. The majority 35% said they had been in Harrow between 11 to 15 years, and 24% said they had been in Harrow more than 15 years. We asked them how long they had been living in UK and the majority 35%, had been here between 11 and 15 years, while 12% had been in UK between 21 and 30 years. Just over a quarter of the people asked had been here under 10 years.

When we asked the same question to the carers, 13% had been here in Harrow under one year, 19% had been here between one to five years, and another 19% between six to 10 years. A quarter of them had been here between 11 to 15 years, and another quarter had been living in Harrow for over 15 years. When we asked them how long they had been living in the UK 6% had been here up to five years, 13% from six to 10 years, 25% between 11 and 15 years, and 31% of the majority between 16 to 20 years. Another 25% had been in UK from 21 to 30 years.

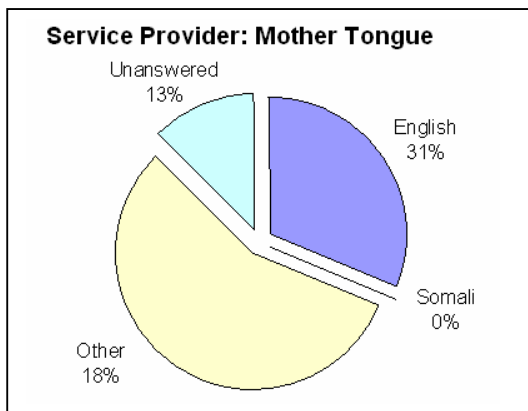


The service providers were asked how many years they had been living in Harrow. 56% said they had been here for less than a year or they lived outside of the borough, 6% were in Harrow for one to five years, 19% for between six and 10 years, 13% for 11 to 15 years, and 6% had been here for more than 15 years.

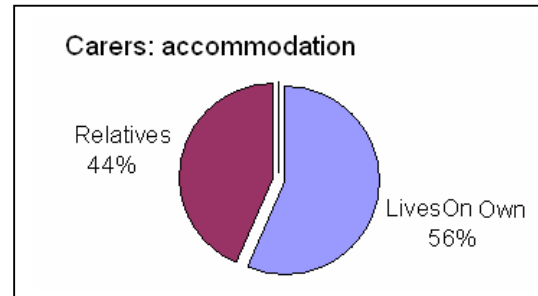
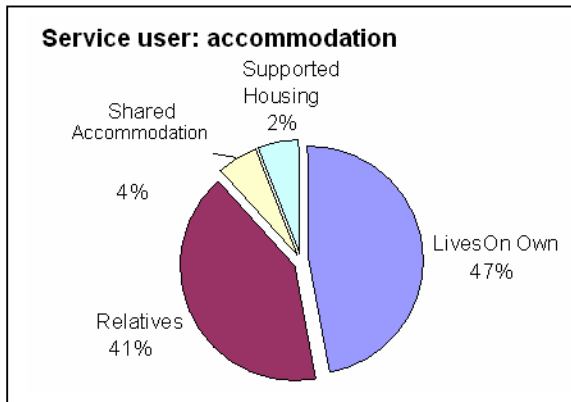
We asked how many years they had been living in the UK, and the majority of them 31%, said they had been here for more than 30 years. 13%, said from 21 to 30 years, 19% from 16 to 20 years, 13% from 11 to 15 years, and at 19% from between six to 10 years in the UK.



2.vi. Fluency in English. All service users had their mother tongue as Somali, 28% felt they were excellent in English, while 24% felt they were good, 12% felt they were average, and 36% had poor English, or no English. Just under 50% of service users said their English was average, poor, or none. It may be significant to offer ESOL classes to new migrants, to diminish effect of lack of language. When asked about their fluency in English, 44% of the carers said their English was excellent, while 50% said it was good. The final 6% said their English was just average.



When we asked the same question about fluency to the service providers, 100% of them said their English was excellent. Of those, 31% said their mother tongue was English and 56% said it was another mother tongue. These latter included Arabic, Cantonese, Ibu, Pigeon English, Punjabi, Urdu, and Zulu/Ndebele.

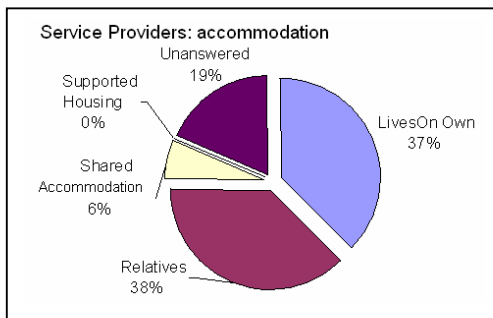


2.vii. Accommodation. We asked the question about residency and accommodation, because this seemed to be so important to the service users and their families. Just under half, 47% of service users, said they lived on their own, while 41% lived with relatives. 6% were in shared accommodation, and one was in supported accommodation. Of the carers, 56% said they lived on their own, and a 44% with relatives.

Service Users: accommodation	Number	Percent
Rented flat or house	2	12%
Council accommodation	5	29%
Housing association	8	47%
Private rehab house	0	0%
Government rehab house	1	6%
Acute psychiatric ward - forensic	1	6%
	17	100%

Service users were also asked where they were currently living. The majority, 47%, were living in a housing association, 29% were living in council accommodation, and 12% were living in a rented flat or house. One person was living in an acute psychiatric ward.

The majority of carers that we interviewed, 63% were living in housing association accommodation, while 19% were in council accommodation, and 6% were in a rented flat or house. 6% said they were living in a privately owned home, and another 6% said other but didn't specify what.



Service Providers Accommodation	Number	Percent
Rented flat or house	4	25%
Privately owned home	11	69%
Unanswered	1	6%
	16	100%

The service providers were asked the same question: 38% said they lived on their own, and another 38% lived with relatives, while 6% lived in shared accommodation. Some of the service providers did not see the relevance of this question, and 19% did not answer it. Of those who answered the question, the majority 69% lived in a privately owned home, while 25% were in rented accommodation. One person did not answer this question. The question illustrates the different standards of living between service providers, and service users and their families.

2.viii. Occupation of respondents:

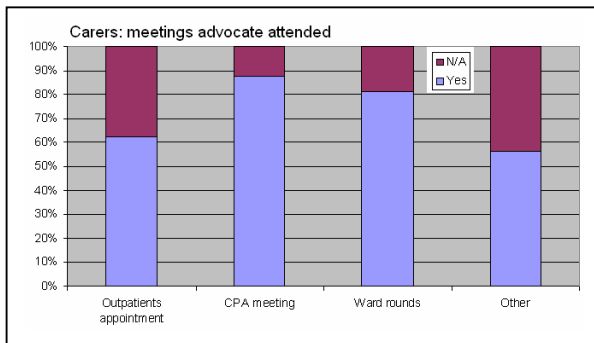
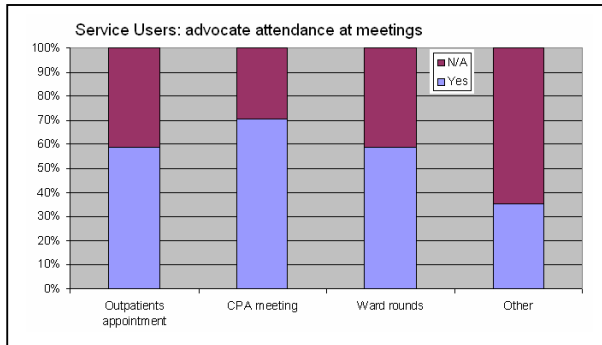
The following occupations were collected in the questionnaire from respondents.

Occupation / Education of Service Users
Bakery supervisor
Language college students
A levels
Housewife
Computer Certificate
None = 11 responses

Occupation / Job Title of Service Providers Interviewed
Clinical Nurse Specialist
Mental Health Nurse
Home Manager
Support worker
Staff nurse
Social Worker
Social Care Assistant
Clinical team leader
Senior Practitioner CMHT
Community mental health nurse
Psychiatric Nurse
Consultant Psychiatrist
Children's Services
Mental Health Housing Liaison Officer
Senior Occupational Therapist

Occupation / Education of Carers
Journalist / Interpreter
Self Employed
house wife carer
Bachelor Degree of Arts
HND in Social work
GSE Health & Social Care
Colonel Somali NM
Restaurant Admin
Bus Driver
Volunteer working in school
Ingredient supervisor, warehouse diploma in computer IT
Voluntary community worker x 3
None = 7 responses

3. Advocacy and Meetings



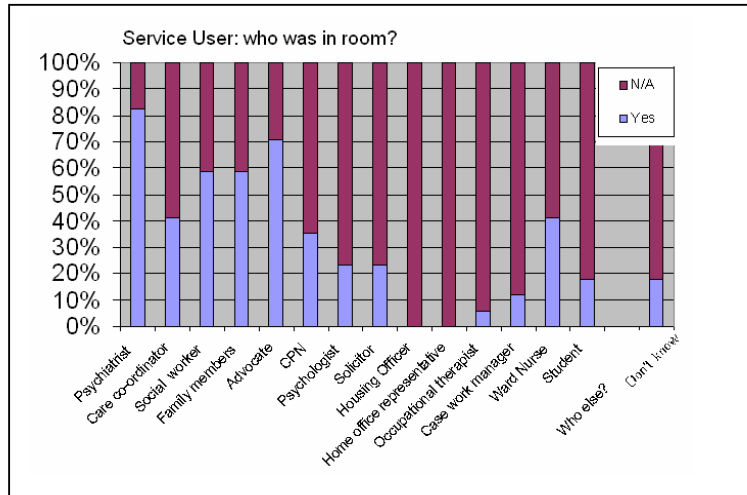
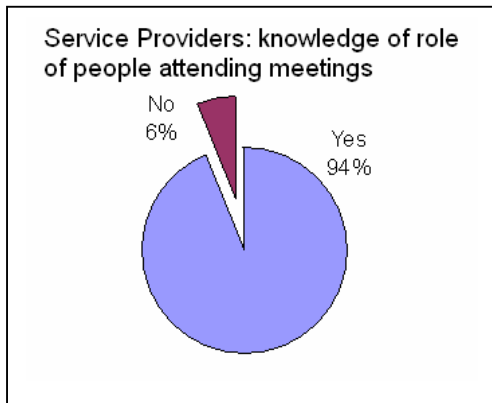
3.i. Advocate attendance at meetings. We asked the service users whether the advocate had ever attended meetings with them. The majority of them said they had been accompanied for outpatient appointments (60%), the Care Plan meeting (70%), and on the ward rounds (60%). They said the advocate also attended meetings with them and family members, at the hospital and for advice, support and counselling.

The carers gave even higher numbers of advocate support during meetings, for example nearly 90% for CPA meetings. He also supported them with home visits, at in-patient meetings, and at social gatherings.

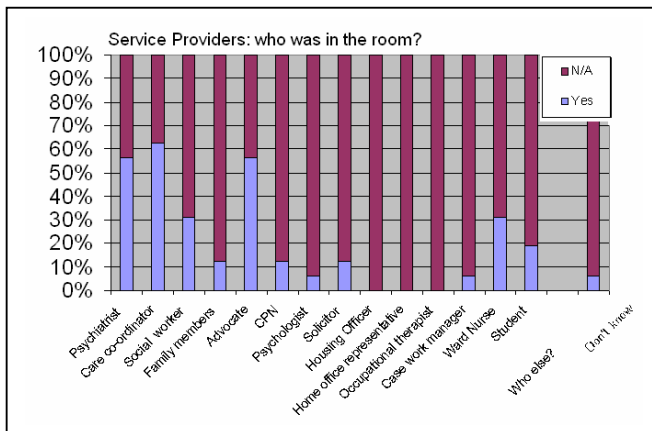
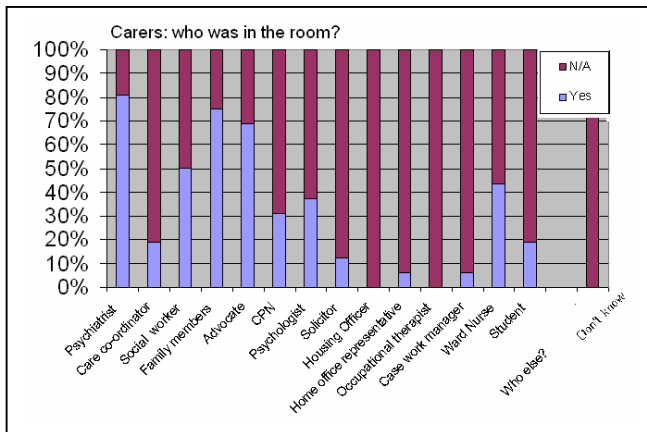
Service providers said he helped with assessments to address language barriers, at case conferences, at mental health review tribunals, and at patients' hostel for CPS reviews. He made home visits, and helped with occupational therapy assessments.

The advocate also helped users out at social gatherings and with family meetings. He assisted service providers and users at assessments, case conferences, mental health review tribunals, and home and hostel visits.

3.ii. Role of people at meetings. Service user interviewees were asked how many people had attended their most recent meeting with professionals and 71% said they knew the role of each person attending, but 29% said they did not know the role. Of carers 69% knew the role of the people attending. Only 6% of service providers did not know the role of all people in the room.

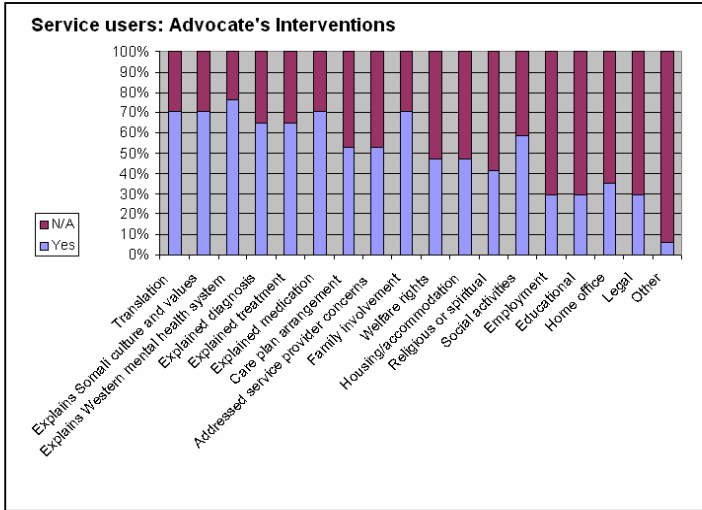


Respondents were asked who was present in the room during their most recent meeting: 82% of service users were aware that the psychiatrist was in the room, and 70% that the advocate was in the room. The figures for others are given above, and these include the care coordinator, a social worker, other family members, the CPN and the ward nurse. Sometimes, there was a solicitor present or a housing officer. The awareness of carers of the role of people in the room is set out below. This is followed by the graph of service providers, who were also asked to note down those people in the room at the last meeting with their Somali patient. The people they remembered were junior doctors, dual diagnosis worker, floating care worker, translator, support worker from the residence, and the befriender.

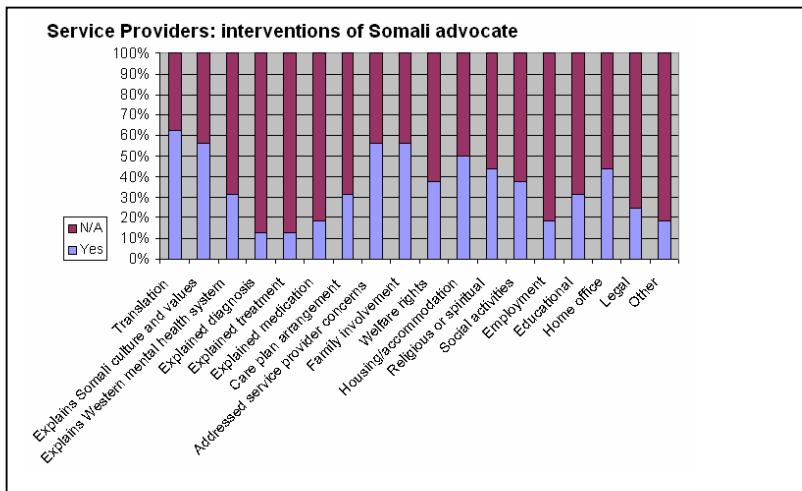


3.iii Advocacy interventions. Interviewees were asked what kinds of intervention the Somali advocate assisted them with. There was a difference between the kinds of advocate activities that users, carers, and service providers noticed. 70% of service users said he helped with translation and explaining Somali values and culture to the professionals. 76% said he helped them to understand the Western mental health system, and over 60% said he explained the diagnosis and treatment to them. 70% said he explained the medication, and 50% said he explained the care plan arrangement. He also addressed the concerns of service providers and 70% said he helped them become involved with their family again. Just under half said that he helped with welfare rights, housing and accommodation, and employment. He also spoke about religious or spiritual requirements with 40% of them. 30% said he helped them with Home Office applications and legal matters.

Likewise with the carers, he helped with translation, and explaining the Western mental health care system to over 60% of them. He explained about the diagnosis and treatment and the medication. He assisted 80% of them with the care plan arrangements.



Service providers said that the advocate helped 60% of them with translation and 57% said he explained Somali culture and values. However, only 30% of them felt that he explained the Western mental health care system, and even less, 12% felt that he explained the diagnosis and treatment to the patients and carers, while 18% felt he explained medication. Over 50% said that he assisted with their concerns, and ensured that family members were involved. 50% said he helped their patient with housing and accommodation, and 40% with religious and spiritual matters, 38% said he helped with social activities and 18%, with employment, 30% with educational matters. Over 40% said he helped their client with Home Office and legal matters.



One service provider explained what the advocate did: *'He translated and interpreted for the family. He addressed the service provider concerns. We had enhanced family involvement. He was able to explain, in cases of domestic violence, exactly why the children could not stay with their father'* Another explained: *'One of my clients had problems and never cleaned his room, he had poor hygiene, but after the advocate came he started cleaning. And our relationship got better.'* One service provider said: *'The residents felt more empowered when he worked with them. There was someone to listen to them. He helped with translation, part of the care plan arrangement. He created a place where mutual understanding could take place.'*

Advocate's activities.

Interviewees were asked if the advocate had helped them in any other way, other than those already mentioned, and many positive activities were mentioned:

- Immigration services
- Resolved issues with family
- Emotional and moral support
- Social, family relations revived
- Reassurance and support in being heard
- Moral support and social integration of our patient
- Made job easier, by explaining procedures and policies
- He helped to build trust between clinician and the patients
- Out of hours calls communicate any progress or help needed
- Improved trust with Harrow mind health service providers
- Cultural sensitivity, challenging assumptions and cultural awareness
- Deepened understanding of client and Somali culture: client was more relaxed

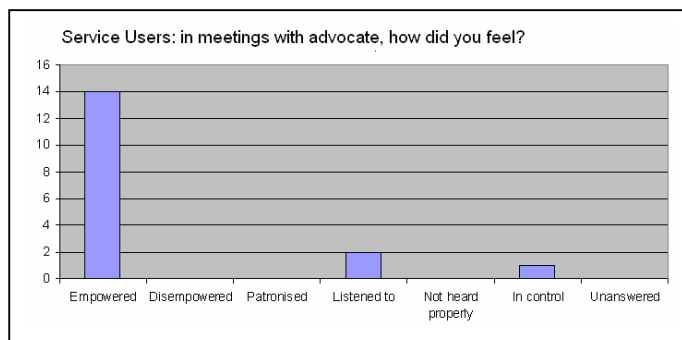
3.vi. Effect of Somali advocacy meetings on well-being

Response to advocate's presence. Interviewees were asked how they felt during meetings with the advocate. This was asked of all three groups, i.e. the service providers, the service users, and the carers. 82% of service users said they felt empowered. When the advocate was at the meeting with them, 12% said they felt listened to and 6% said they felt more in control.

Interviewees were asked, what meetings were like before, the advocate was supporting them. Six service users replied that it was '*not good*', and others said that it was: '*bad, didn't know what was going on*', '*stressful*', and '*it was difficult to explain things to the doctor*'. One said '*the meeting was not flexible before the advocate attended*.'

Service users said, that before the advocate attended:

- *I never understood what was going on*
- *I never understood and it was awful*
- *Felt I didn't have any future.*
- *Suffering distress.*



Carers: During meetings with advocate, did you feel...?	Number	Percent
Empowered	11	69%
Disempowered	1	6%
Patronised	0	0%
Listened to	3	19%
Not heard properly	1	6%
In control	0	0%
Unanswered	0	0%
	16	100%

When the carers were asked the same question, 69% said they felt empowered, and 19% said they felt listened to. However, 6% said they felt as if they were disempowered, and had not been heard properly. One person said they were not allowed to be in the room during their relative's meeting. One woman said: *"He helped me put my brother in a care home, because I was looking after him for such a long time. He was with me at home. Before I felt no one really cared. My brother hit me just once, and I had to call the police. I don't take violence from anybody."*

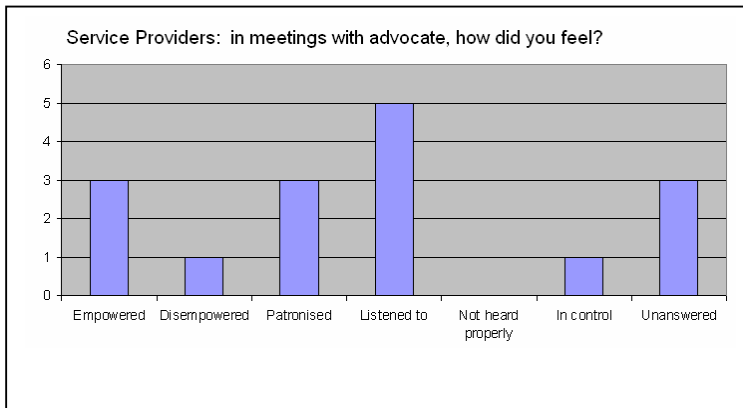
After the advocate attended meetings, it helped the patients to calm down. The meetings were well organised and understandable, and users and carers felt they could make more informed decisions. The patients were more willing to co-operate with the doctors, and they saw there was a clear action plan. After meetings with the advocate, respondents felt there was a change. The service users said:

- *Communication improved and I felt more comfortable*
- *The advocate helped me a lot and am now feeling happy and expecting a good future*
- *He helped understand my illness more*
- *It became okay*

Carers said that meetings once the advocate was there were well organised and understandable, and they helped the patient to calm down. They said:

- *Situation became clearer, patient more willing to cooperate.*
- *Since the advocate attended, the meeting has changed and been helpful and useful.*
- *In the care home people gave him a lot more care. I recommend the care home. He got the correct medication.*
- *After giving advice our family became more aware of the health situation of my brother.*
- *I was allowed to sit in and observe.*
- *We had an action plan*

Carers said *'it was very supportive, due to advocate intervention'*. One said *'He was there to help me and explain things to me so that I understood what it was all about.'* However, three carers said they felt patronised.



Service Providers: During meetings with advocate, did you feel...?	Number	Percent
Empowered	3	19%
Disempowered	1	6%
Patronised	3	19%
Listened to	5	31%
Not heard properly	0	0%
In control	1	6%
Unanswered	3	19%
	16	100%

The response of service providers was different: 19% felt empowered, and 31% felt they had been listened to. However, 19% of the service providers felt that they had been patronised, and 6% that they had been disempowered. Before the advocate was employed, they said that the client used to avoid attending the mental health services, and when they did, it was unclear what they wanted. The background history of the patients was not so accessible, and there was a lack of understanding about culture, language barriers, and individual histories. Clients were more anxious, as they were less able to express their views.

After the advocate came the service providers were grateful for the help with translation and interpretation, which enabled the meetings to feel more comfortable, and be more fruitful. One said '*Client opened up, made it easier to make assessments*', and another explained '*one of my clients had problems and never cleaned his room. He had poor hygiene, but after the advocate came he started cleaning, and our relationship got better*'. Another said '*the advocate gave the mother a chance to voice her opinion*', and '*client gradually engaged more with us*'.

Some of the service providers were unhappy with the input of the advocate, and felt it hadn't made much difference to their practice. One found him very forthright. Another considered that his presence had a negative impact, resulting in '*miscommunication, confusion of roles, difficult team work, affecting relationship of other professionals*'.

One said '*Patients were told that the mental health service was useless*'. Another explained: '*Meetings were sometimes longer with an advocate, though this got better over time. The advocate is valuable to patients. At first his practice was too obvious, and he didn't add much. As he got more confident, his interventions and contributions were more appropriate*'. One professional was concerned the advocate brought his own preconceptions to the meeting and considered this could be challenging for mental health staff.

On a positive note, due to the advocate's presence, professionals felt that they did not neglect the ethnic background of their client, and communication improved. One service providers said the '*client opened up, made it easier to make assessments*' and the '*client gradually engaged more with us*'.

Chapter 4. Cultural Concerns

This part of the report which addresses cultural concerns, and has been divided into five sections:

- 4.1. Importance of Personal Histories
- 4.2. Cultural Understandings and Values
- 4.3. Concepts of Confidentiality and Privacy
- 4.4. Cultural Concepts of Mental Health
- 4.5. Cultural Practices and Mental Health
- 4.6. Importance of Training and Culture

4.1. The first part explores respondents' attitudes to service users' personal histories and narratives.

4.2. The second part, on cultural understanding and values, covers the following topics:

- Somali Family Models
- Cultural Concept of Family
- Female advocates
- Somali cultural values

Service providers alone were asked a series of questions, which users and carers were not asked. These include questions about: Somali Family Values; Somali Cultural Values; and Somali concepts of privacy and confidentiality.

4.3. The third part presents all participants' responses to questions about concepts of privacy and confidentiality

4.4. The fourth section presents the data from the questionnaire about cultural understandings of mental health and practitioners.

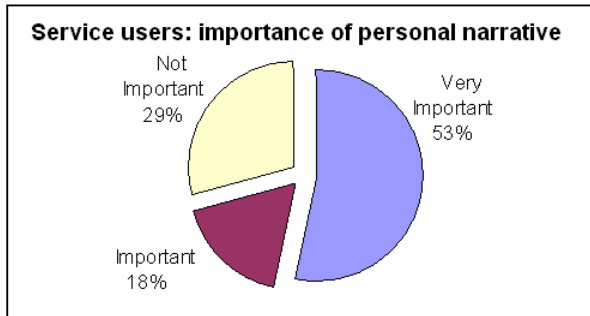
This part, on cultural concepts of mental health, explores respondents' understanding of the term 'mental health'; their beliefs about illness causation, in general, and in specific terms. It also explores the effects of illness on daily life, and the adjustments required to cope with it.

4.5. This section explores cultural practices and mental health. It enquires about the kinds of practitioners available in Somalia to address mental ill health, and the alternative and complementary practitioners available to Harrow residents.

4.6. The last section presents respondents' answers about the importance of training in cultural matters.

4.1. Importance of Personal Narratives

All respondents were asked if it was important to hear of person's story in order to understand their history. When the service users were asked, 53% of them said it was very important to hear of person story, 18% said it was important, and 29% said it was not important. Seven people did not answer this question.

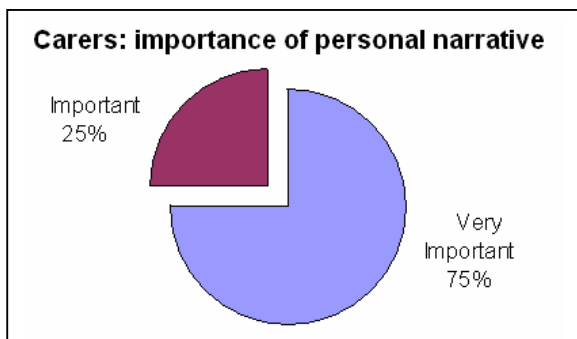


Service users gave various reasons as to why their narrative should be heard, and these included because it would help professionals to better understand them, and to determine the most appropriate treatment. It would also help service providers understand the differences between cultural practices in Somalia and here in Harrow. One said: *'History has a lot to do with a person.'* They feared: *'If the doctor does not know person's history, he does not find your treatment.'* Another repeated this: *'Without person's story it might be difficult to get the right treatment'*. One person explained that patients had a certain kind of knowledge about themselves.

They also mentioned the following reasons to hear their story:

- *it helps the service provider to find out his/her illness and exact treatment he/she may need.*
- *Some may see it as wrong to ask their story but it is very important for diagnosis of mental illness*
- *Treatment will be easier and because the doctor and family will easily find the appropriate treatment for the patient's needs.*
- *In terms of community, it helps people to understand the cultural variation that exists between here and back home*

Carers. The carers were asked the same question about hearing personal narratives and history from countries of origin: 75% of them said it was very important and 25% said it was important. Several felt it would help the professionals get an insight into the patient's problems, to understand the reasons for their mental ill health, and determine the root cause of the problem. One person explained that it was important *'because it can give the professionals an understanding of his/her illness and their hereditary or family background'*. Also that it would help the patient *'feel that they are being listened to'*.

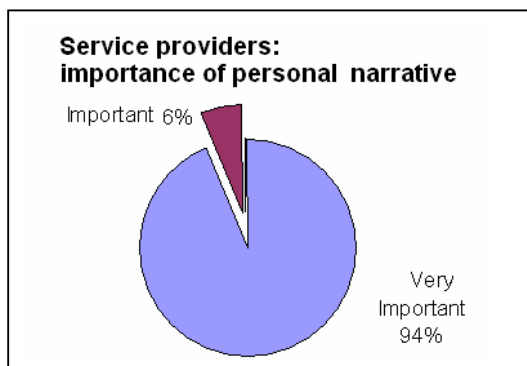


One carer felt it was essential to hear the narrative *'otherwise the doctor can't analyse patient'*. She also felt that her relative should also have access to talking therapies. Another felt that hearing the narrative would help *'to fill the cultural gap between western system and Somali culture in terms of mental health'*. This would make it easier to treat a patient quickly. One said *'their past might have answers to behaviour or illness, and help/support needed for recovery.'*

Carers also added that hearing about a patient's history would help service providers to:

- *Get an insight into the problem of the patient.*
- *Get the background history and become well informed.*
- *Find out the root cause of the problem of the patient.*
- *Treat quickly if professionals have more information about his/her health record.*

Service providers were also asked about whether it was important to hear a person story: the overwhelming majority of them (94%) said it was very important, and 6% said it was important to hear a client's history and personal story, as a way of understanding their mental health. One person emphasised: *'We can't work holistically with problems if we don't know this story.'*



They explained the following: *'It is important to hear a person's history, because it will help to know them better. It makes you feel more empathy'*. Another said that inviting a person's narrative with open questions was a basic skill in psychiatry and psychiatric nursing. It helped staff find out about patient's history, beliefs, values and culture. He said: *'(We) can find out how they see society and what is normal to them, help understand behaviour. (We) can tailor care to their needs.'* One explained that they could trace a person's problems *'through their life story and history and to understand their point of view.'* It helped them to understand why that client was accessing the mental health services, and what their needs were.

Hearing narrative helps service providers develop rapport with the client, and gives a more comprehensive idea of their concerns, particularly if they have experienced abuse. Hearing the narrative gives them a *'better understanding of individual without judgement'*. One person stressed the importance of hearing a client's history because: *'it impacts on current behaviour. It may reflect through their children's behaviour. It may be something that they haven't dealt with, but they need support with'*.

A service provider of African origin explained the need to know the difference between the journeys of people coming from different parts of Africa. He said: *'If you hear a person story, you understand that they are on a journey, and they haven't reached their destination. It helps you to guide them to support them. We need to know the difference between a black African Somali, and a black African Caribbean'*. Another said how important it was to draw up a timeline to understand

how PTSD (Post Traumatic Stress Disorder) originated from the Somali peoples' experience of war. He said: we 'need to know triggers, to recognise issues. It helps to plan care, to know where they are coming from.'

Service providers explained that it was very important as a way of defining the most appropriate treatment, doing a risk assessment, and planning care. They said: '*a good history is a thorough assessment*', and they did it:

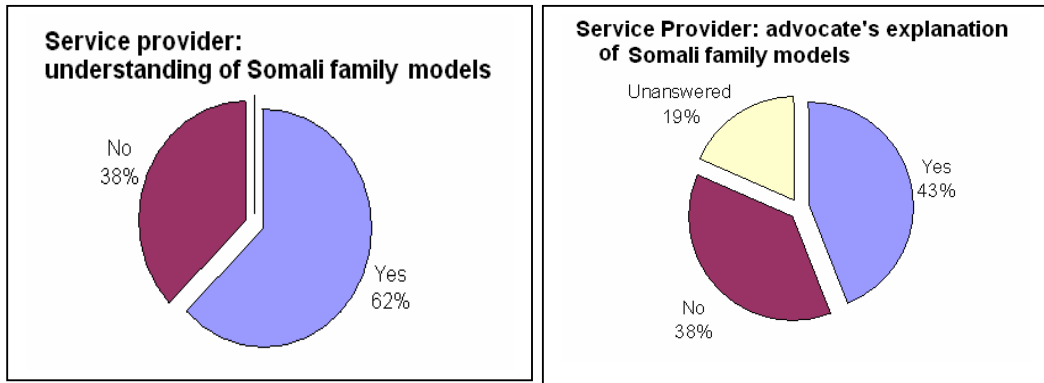
- '*To get a better understanding of person's perspective, their understanding, what they have been through.*'
- '*To understand illness, distress, how to help them, risk, and effective treatment, you have to hear their story to assess the best treatment.*'

The good practice of exploring client's history and their own narrative will be continued, in order to diagnose and treat people appropriately.

4.2. Cultural Understandings and Values

4.2.i. Somali family models.

This question was only asked of service providers. They were asked whether the advocate explained about Somali family models, and whether he supported a dialogue between them and the community mental health teams: 43% of them said yes, 38% replied no, and 19% left the question unanswered.



When they were asked if they understood more about Somali models of the family, as a result of advocacy, 62% of the service providers said yes, and 38% said no.

Those service providers who said that the advocate had explained about Somali family models wrote:

- *Yes, family is community focused, willing to help one another even if not directly related. Tribal allegiance.*
- *Yes. Did observe these differences, more involved, family support, clarifying these differences. Close family support network, share more experiences, supporting each other.*
- *Yes, the advocate did explain about Somali values. I understand that Somali models go beyond the individual alone, they go beyond the nuclear family of just wife and children. Any other people from their country, who come from the same clan and same lineage*
- *Yes. Extended families live together and are classed as brothers or sisters.*
- *A systematic family structure, for the nuclear family and extended family, and other members of their community. It involves more than the Western culture.*

One person said the advocate explained informally about the 'extended family, with community support, managing difficulties within the family rather than to outside services for help.'

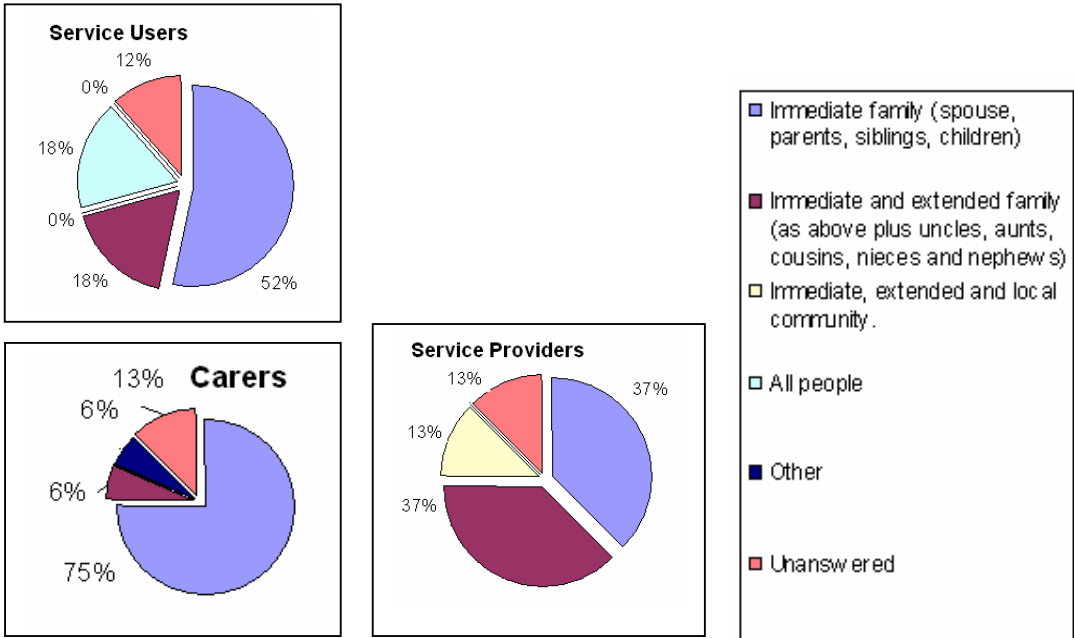
Those who wrote 'no' said:

- *No explanation given.*
- *No. He didn't explain about family models, nor about Somali models.*
- *No. He didn't describe family models, but I have observed family models myself. For example: the men chewing khat, and their wives having to do everything.*
- *No. Asked for help but did not get. Avoids using service due to past experience. Don't understand a great deal, not traditional western model, matriarchal, extended family living together.*
- *Ask if service is suitable. No.*

4.2. Cultural Understandings and Values

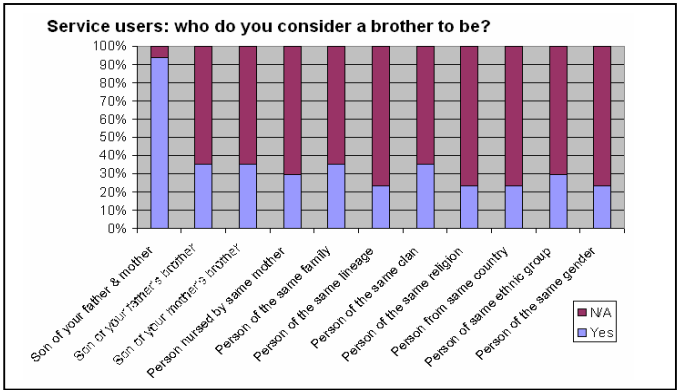
4.2.ii. Concept of Family

We asked all respondents questions about family, as it was obvious before the research began, that there were different understandings of the words: brother and sister. The extended family were important regarding their involvement in their relative's care.



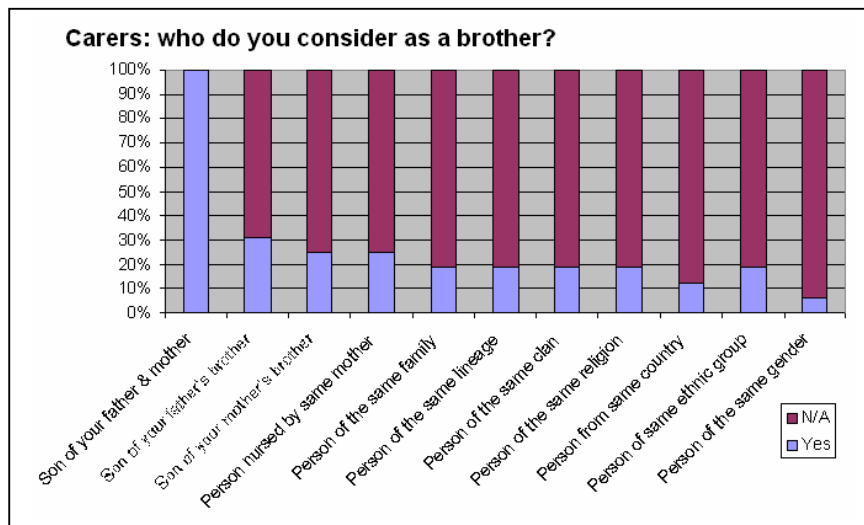
All the respondents were asked which people they would include as their family. They were also asked who they would consider as a brother, and who has a sister. The responses below are divided according to service user, carer, and service provider.

Service users. The service users were asked about family, and 52% of them said that their family would include their spouse, their parents, their siblings and their children. 18% said they would include their extended family: that is their aunts, uncles and cousins, nieces and nephews. Another 18% said that they would include other people as the same family, such as the medical team.



They were also asked who they considered a brother to be: 95% of service users, said it would be the son of their parents, 35% said it would be the son of their father's brother, or their mother's brother. 30% said a brother would be a person nursed by the same mother. 35% considered that a male person of the same family, or clan, would be considered a brother, while 25% considered that a person of the same lineage, of the same religion or from the same country or of the same gender would be considered a brother. 30% considered that a person of the same ethnic group would be considered a brother.

The figures were similar when they were asked about who they considered a sister to be: 95% considered it would be the daughter of their father and mother, while 48% considered a sister would be the daughter of their sister's brother and 40% of the daughter of their mother's brother. Only 10% considered a sister would be a person nursed by the same mother. However 30%, considered that someone of the same lineage, the same clan or the same family would be considered as sister, while 25% considered a female of the same religion, the same country, or the same ethnic group, as sister. Only 10% considered someone of the same gender was a sister.

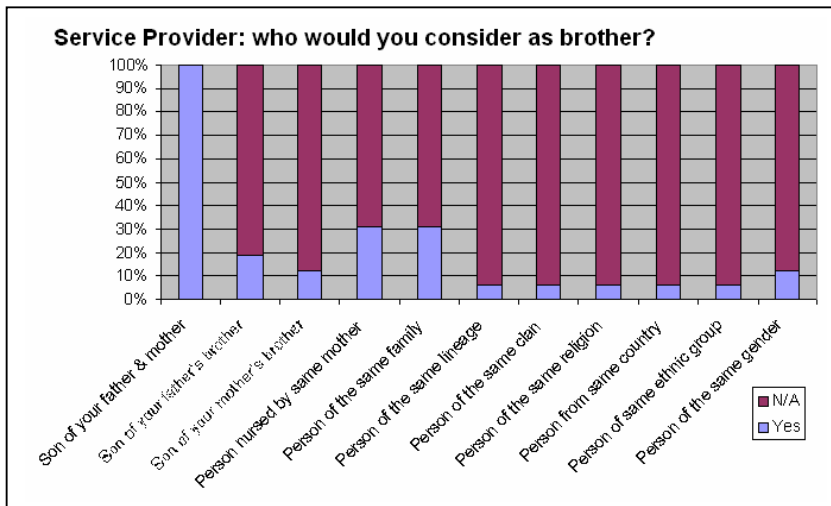


Carers. The carers were asked the same questions, and 75% considered family to be the immediate relations, of spouse, parents, siblings and children. While 6% thought that the immediate and extended family counted. 13% of people did not answer the question. One person considered as family anyone they had shared their life with, or who had supported them in life. 30% of carers considered that the son of their father's brother was a brother, and 25% the son of their mother's brother, including a male nursed by the same mother. 20% considered that a person of the same family, the same lineage, clan, religion, and ethnic group was also a brother. Only 12% said a person from the same country would be considered a brother and a 5% that a person of the same gender would be a brother.

When the carers were asked who they considered a sister to be, all of them said the daughter of their parents, while 30% said the daughter of their father's brother, and 25%, their mother's brother. 20% said that they would consider a sister to be a person nursed by the same mother, of the same family, the same lineage, the same clan, the same religion, the same country, and the same ethnic group. Only 6% said people of the same gender would be considered as sister.

Service providers. Service providers were asked which people they would include as their family, and 37% said it would be the immediate family of spouse, parents,

siblings, and children, while another 37% also included the extended family of aunts and uncles, cousins, and nieces and nephews. 13% of them would include their extended family and the local community, as family. 13% did not answer the question. One person said 'family' depended on who was living nearby, it may be only the blood relations, or it may be distant kin, who lived in proximity to their home. One person explained that all his extended family were abroad. Another said he also considered people in his community as family, and his urban friends, including his close friends and his work colleagues.



When asked who they would consider a brother to be, 100% of them said it would be the son of their father and mother. 30% said it would be somebody nursed by the same mother or belonging to the same family, while 20% said it would be the son of their father's brother and 10%, the son of their mother's brother. Only 6% said it would be the person of the same lineage, clan, religion, country, and ethnic group, who would be considered a brother. 12% considered that a person of the same gender was a brother.

When asked who they would consider a sister to be, 100% of service providers said it would be the daughter of their mother and father. 30% said it would be a person nursed by the same mother, and 25% said they would be somebody of the same family. Only 20% said it would be the daughter of the father's brother, and 12% the daughter of the mother's brother. Only 6% considered that somebody of the same lineage, clan, religion, country, ethnic group and gender, would be considered as sister.

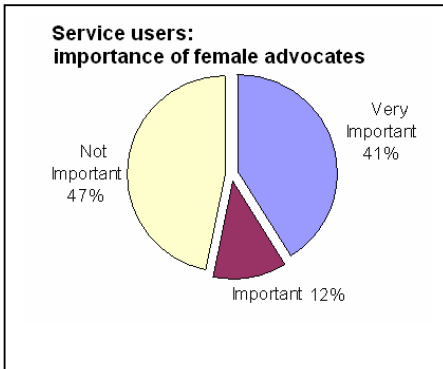
Although none of the service providers interviewed in Harrow, were of Somali origin, they were from many different places of origin in the world. Their ethnicity, race, and cultural backgrounds, influenced their responses to these questions. One man explained to us: *'a brother can be a blood brother, but since I have been in this country, brother is also a friend. I see my friends as my brothers. Anybody. I don't have other relatives in this country, but I have a wife and kids.'*

Another service provider of African origin said: *'In the African culture, anyone who is related to you in some way is a brother. Anyone who speaks your language is your brother. When the word brother is used, it can be any other person who lives or works with you, who is of the same gender, same religion, same clan. All of this.'*

Another said with regard to sisters, that her cousins were like sisters, as were the female relatives of her mother and father, and also she said her friend was a like a sister to her.

4.2. Cultural Understandings and Values

4.2.iii. Female advocates



All respondents were asked whether they considered it was important for women to have female advocates.

Note: In some societies, women are given different values to men. In the case of Harrow, there was only one advocate who was male, whereas other London boroughs had both male and female advocates, e.g. at Midaye in Kensington and Chelsea, where there were proportionally more female service users.

Service Users. 41% of service users said it was very important, and 12% said it was important, while 47% said it was not important.

Those service users who said it was important to have a female advocate gave the following responses:

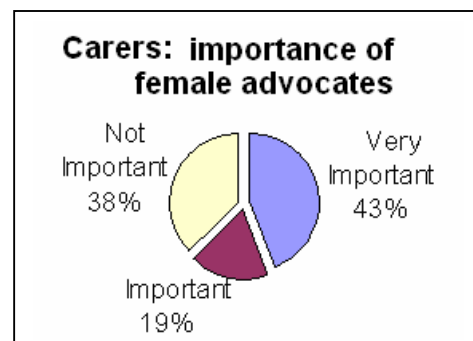
- *Women are more vulnerable than men.*
- *Women prefer to talk with a woman*
- *They have a better understanding of women's values and problems.*
- *For religious reasons, females can feel more comfortable with another female*
- *Important for women to be able to tell their stories in order that their health needs are understood.*
- *Female needs to tell their story with another female*
- *It helps doctors to find exact treatment for patient*

Some felt that women would open up more with a female advocate, whereas those who felt it did not matter said:

- *It's the same with men and women*
- *As long as the advocate supports me, it is the same either male or female.*
- *I'm comfortable discussing issues with anyone*

These points were made while the majority of service users interviewed (67%) were male. One person was worried about gossip and said: '*Women have no strength for confidentiality*'. However, gossip can be both a male and a female trait.

Carers. When the carers were asked the same question about female advocates, 43% of them said it was very important, 19% that it was important, and 38% said it was not important.



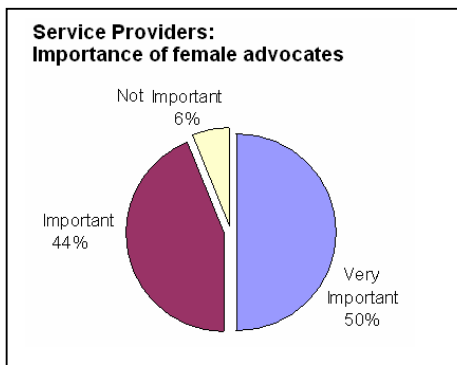
Those who felt it was important to have a female advocate said that it was necessary due to cultural and social necessities. They feared men would misinterpret their narratives, and they could not mention their personal private concerns in front of men. One person explained: *"Women understand, you can't talk to men, or they misinterpret. 100% we should have a woman who understands. There are some things you cannot talk to men about"*. Another said it was important to be sensitive to the requirements of different genders, and would also prefer female translators. One explained that Somali women can not tell their story or recount private concerns to men:

- *we can't discuss everything with a man*
- *Because women feel it's easier to talk another women*
- *The patient may find it difficult to share personal information with opposite gender*
- *Due to cultural and religious aspects, it is important to have a female advocate*
- *Females need their own female advocate to feel more comfortable.*

Similarly, there were carers who said that it was not necessary to have a female advocate. We note that these points were made while the majority of carers (67%) were male. Carers said they were *"Comfortable discussing issues with anyone"*, and:

- *Shouldn't matter if male or female*
- *Not necessary for a woman to have a female advocate*
- *Depends on the personality of the person, the gender does not matter*
- *Depends on the individual. I feel now more women are allowed to be seen by different gender doctors so it would be OK for the majority.*

Service Providers. Service providers were asked the same question about female advocates: 50% of them said it was very important, 44% that it was important, and there was only one person (6%) who said that it was not important. Again there were the same proportion of male to female respondents as the users and carers, but the service providers were almost unanimously in favour of having a female advocate.



Service providers mentioned that it was important to have an awareness of both African culture and Muslim cultural norms when discussing this issue. They said that they felt it may not be so important in western society, but sometimes among the Somali community *"women are not viewed as equal so would need a female advocate"*. They said it would be difficult for a Muslim Somali woman to talk to a male advocate openly about personal issues. They noted that there was a need for choice, as female patients may have concerns around talking to men, as they may have had *"previous traumatic experiences with men"*. One said:

- *"If a woman is discussing something personal to them, especially an incident of domestic violence, they may find it difficult to have a male advocate. It's also important to give women choice."*

They acknowledged that some female clients may only want a female advocate, as *"it would be easier for women to understand each other"*. They noted that there was gender inequality in some patient's countries of origin, and women advocates were better if clients were to talk more openly, with more honesty about women's issues. Although one person noted that a *'male advocate is better than nothing'*. Another said that having someone with the role of advocate was more important than their gender.

However, another said that among some cultures and with people of certain faiths *"it may not be reasonable to have a male professional, as (women would be) unable to be open with him to discuss personal issues"*. Those women who have experienced abuse, and disempowerment, they would find it *"difficult to discuss personal issues."* One service provider expressed concern that in meetings the Somali advocate tended *"to talk with the spouse, with the male partner, and didn't take account of the female patient's viewpoint."*

Service providers were explicit that there was a need for choice, for both male and female advocates. They said:

- *You need both men and women.*
- *Females feel better talking to females. Have both genders.*
- *Clients, even though they are men, they feel comfortable speaking to female advocates.*

One person said: *'If you have an advocate, who is speaking on your behalf, it may be particularly difficult for some women to have a male advocate present, while discussing a particular issue. I know that some of my clients asked for female staff, because then they are more comfortable speaking about their concerns.'*

This fact was emphasised by another service provider, who also had concerns about the treatment of female patients. He said: *'There is a bias and an undermining of female patients. The judging of the services of mental health here is also biased. There is a bias towards people of one part of the country of Somalia, and not the others. There is an under estimation of the importance of Somali interpreters, especially female interpreters. We need mixed gender in that role, and as interpreters.'*

Another person said the advocate claimed 10 complaints against the translating service, and he offered to set up a meeting. He said *"if you're talking about a specific agency and say there are 10 complaints, you need to provide evidence, and work it through on a case-by-case basis. I tried to work with the advocate over this, but he didn't provide any evidence, so there was nothing I could do"*.

Service providers had other concerns apart from gender issues, about the problems between Somalia and Somaliland. One said: *'There are different dialects, and one translator may have come from one place of origin, which is at war with the client's place of origin, and this may cause upset.'*

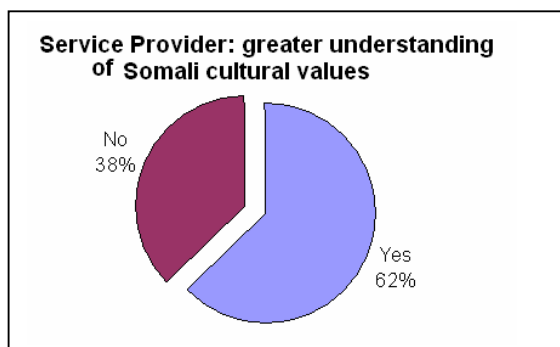
One service provider also commented on the need to be aware of generational differences that may exist between a client and an advocate: *"we need an open-minded person as an advocate, as younger Somalis who are not living a traditional life may feel threatened by an advocate, who is coming with a very traditional mindset."*

Service providers' responses explain that some feel they have experienced discrimination towards their female patients, and emphasise the need for female Somali advocates to support Somali females who need to use the mental health service in Harrow.

4.2. Cultural Understandings and Values

4.2.iv. Understanding of Somali Cultural values

Service providers alone were asked whether they had gained an understanding of Somali culture as a result of the advocate's interventions.



When asked whether they understood more about Somali cultural values and mental health as a result of the advocate's intervention, 62% of service providers replied yes, they had understood more, and 38% replied 'no'.

Once again service providers' answers were polarised when they responded to questions about the advocate's interventions around explaining family values. One said: *'I have learned more about Somali culture and the food that they need cooking, and I can speak a little bit of Swahili. I have learned more about Muslims and their religious holidays, and what to be buying for them. The advocate has been very helpful'*. Two persons had learnt more about the tradition of taking Khat, the socialising that went with it, and the need to cut down consumption.

The advocate helped staff understand about: *'family colluding with patient'* and about *'community cohesion and bonding'*. Respondents realised that people had different kinds of understanding about mental health. One service provider considered that more empowerment was needed *'to get women into education'*, and several people mentioned the need to address cultural beliefs of shame and stigma around mental health issues.

Another service provider explained that he had learnt about: *'delusions relating to religious beliefs and decisions around religious practice... their family situation and culture, speaking in family terms, their sense of extended family, their understanding of medication and reluctance to engage in services.'*

This was confirmed by another respondent who understood that Somali people don't feel the services can meet their needs. Others had learnt that Somali people had a different understanding of mental health and of the services that could be provided. One said: *'They didn't take mental health seriously. They won't involve family, unless police are involved. People keep them in their home.'* One had learnt about: *'working with the whole family and being more relaxed with confidentiality issues'*.

Others said that hadn't really learnt much from the advocate, and felt they would need to meet with him more often. One person said *'We haven't had any discussions, other Somali people helped more'*. One respondent said he: *'didn't think understanding was relevant to job'*. He continued: *'(I) learnt about different*

mannerisms and behaviour of people but not mainstream Somali people if unwell'. Another said 'Understanding about Somali culture, is not something that has been brought up.'

Respondents were asked how the advocate explained cultural and family values to them. Respondents said:

- *Advocate volunteered required information, explaining misunderstandings.*
- *He explained Somali values to me, and explained western values to them.*
- *Advocate was very helpful.*

Other service providers learnt through their own initiatives:

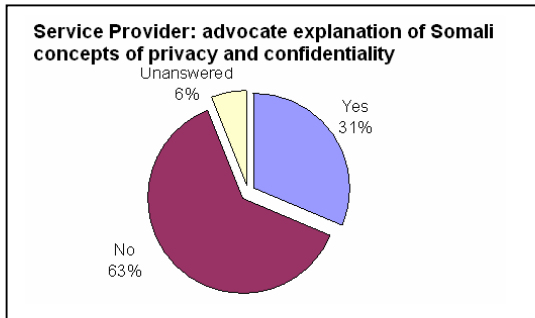
- *Through team work, education about different cultural beliefs, own studies, not through advocate.*
- *Through their own effort to learn about values.*
- *Advocate hasn't explained them.*

One service provider of African origin was frustrated and concerned about Eurocentric ways of understanding mental health, and emphasised how important it was to know about culture. He said: *'from a Eurocentric perspective, people just don't get it, they just don't understand. It is important because the understanding of culture is what helps people to get better. There are things that happen in African culture, that may not be acceptable in European culture, but it is their way of life, it doesn't translate to a diagnosis of badness.'* He continued: *'there are a lot of cultural things that I feel the Western culture needs to understand about, and not pathologise'.*

Given the responses above, it seems we need more mental health promotion among the Somali community, to address stigma, and offer support, so that people with mental health problems are not kept hidden at home by their families.

4.3. Somali Concepts of Privacy and Confidentiality

Service providers were asked a question about whether the advocate had explained to them about Somali concepts of privacy and confidentiality: 31% replied yes, 63% replied no, and 6% left the question unanswered.



One person thought confidentiality may be more to do with religious needs and diet, and the problems for Muslim women on open wards, with male doctors going in to check on them. They also mentioned about difficulties with conducting physical examinations, asking personal questions, and said it was difficult to get to the bottom of problems. Another said: *'We don't talk with people outside family, in cases of family conflict, or when we don't know the family dynamics.'* One person was concerned about the lack of male role models within the family. Another understood that mental health was often understood within the framework of religion and culture. Another said no explanation was given.

Those who said 'No' felt that the Somali advocate should have explained more. One person said he became aware of these concepts after working closely with Somali clients: *'He didn't explain about Somali concepts of privacy and confidentiality, but I did get the hang of it, after working with clients. I worked out that there seemed to be no such thing as a Somali concept of confidentiality.'* Another person noted the different ways of thinking about confidentiality: *'The Western culture may have one particular understanding of boundaries, but the Somali don't have it.'*

4.3.i. Confidential Meetings. Respondents were asked, in a confidential meeting between a health care professional and a patient, who they thought should attend.

Seven of the service users said that family members should attend, while four said the advocate should attend, and five people didn't answer the question. Those who did respond said:

- *Family should go and attend the meeting in my opinion. It is important to share with patient's information with their parents.*
- *Advocate should attend confidential meeting with doctor, and a member of family.*
- *Family involvement is very significant, when it comes to meeting between the patient and professional.*
- *Family and friends.*

Twelve of the carers replied that family should attend confidential meetings (close or immediate family), while six said that an advocate should be present, and three didn't answer the question. One person said a translator should be there. They said:

- *Very close family, and other person who can understand or have basic knowledge of the problem.*

- *Family should attend these meetings because they must know the patient's problems.*
- *It is very important that relatives of the patient attend the meeting along with practitioners.*

The service providers said the kinds of people who attended a confidential meeting depended on the requirements of the case and the wishes of the service user. There could be various members of the interdisciplinary team as well as students present in the room. Children would be asked to leave. Ten people mentioned that those who attended had to be with the consent of the patient. They explained:

- *Depends on the patient's wishes*
- *Consultant, care coordinator, advocate, key worker. Sometimes I have go through the social worker, sometimes the police.*
- *Me and the client, any other professional concerned with his case with consent of client.*
- *Up to client, who they want to share the information with, take into account person's mental capacity.*

4.3.ii. Sharing information. Respondents were asked with whom mental health professionals should share information about a patient.

Ten of the service users said information should be shared with their family, two mentioned it should be shared with the advocate, and two mentioned that it should be with consent. They considered that family being included '*was crucial*', or anyone who the '*patient had given authority*'. Four people didn't answer the question. The carers were asked the same question. Eleven of them said professionals should share information with the family, seven said it could be shared with the advocate, and two mentioned patient consent. One was concerned about her relative's condition being mentioned inappropriately, if they were seen by Somali people: '*Someone who can keep confidential my brother's medical records. My brother's health records should not be in the community*'. Others said close family should be included:

- *Relatives or closest one in his/her family, with permission from the patient.*
- *The information or the record must be shared with family only, except for the mental health professionals.*

Service providers were also asked who they should share information with. Seven of them mentioned patient consent, and four mentioned the guidelines about the regulations.

- *I share information with the patient, and if there are other organisations that need to know that information, I invite the patient to sign a consent form.*
- *Abide by the regulations of confidentiality, and get consent from the patient, on who they think is important and supportive.*
- *Strict guidelines to follow.*

Some mentioned that only some information should be given to the next of kin, while it could be shared with mental health professionals who were directly concerned in the patient's care.

- *Any mental health professionals - solicitor, police, only some selected information to the sister - as next of kin.*

Others say they want to share information with relatives, but the service user refuses:

- *We share information with the same ones (in meeting), and with the authority for the residence. Sometimes we want to invite their relatives, but they say no, and then we can't disclose.*

They would expect to share information with the multi-disciplinary team that cared for the patient.

- *The staff concerned with the patient's care, but not necessarily with a GP, unless the patient asks. Unless the patient is at risk.*
- *School, GP, health visitor, other professionals. Only if client gives consent. We have a duty to do statutory checks to ensure that the child is safe. If there are concerns for their risks, we may bring in police. We follow data protection guidelines.*
- *Confidentiality, who needs to know. There are some issues that a patient may only want to be known on a one-to-one basis, and there may be other things, where other people need to be involved cover other professionals who will care for them.*

Respondents were also asked whether they thought a mental health professional should share details about a patient's case with family members.

Eight of the service users said information should be shared with their family, 'Yes, of course', but six did not answer this question. One mentioned consent, and one said no, that it was his family who had caused the problem.

Twelve of the carers said information should be shared, with one person mentioning consent, and one fearful of gossip. They said:

- *Yes, of course family should be respected their view is very important.*
- *I don't think people should tell their wife. If they see my brother. Only those who are working with them.*

The service providers were very aware about consent, and mentioned the need for patient consent 15 times. One said he didn't usually share information, but he had to with his Somali patient:

- *No, but had to with Somalis. If the client is happy and willing, then I would share information with the family. It depends what the client wants. That is the key.*

While another said that the patient did not agree with family members knowing, however, sometimes it was important for family to know:

- *There are some patients who don't agree to their family members knowing about them. It depends on the patient's wishes, and also on the patient's health and safety. Sometimes the family members are vital, for example, if we are going to offer liberty*

In cases of risk, or where the patient will go back to living with their family, it was important to share details with them

- *With consent, unless risk is identified to family members living with client then sharing is necessary.*
- *Only with their permission or if there are overriding risk concerns.*

They mentioned that it may be good to help the carer's understanding of their relative, but one person mentioned that information could lead to family conflicts.

4.3.iii. Meaning of 'confidential'. Various meanings were given for the word confidential, and for service users (5 of whom didn't answer) these included:

- *Information that is not allowed to be shared with other people.*
- *Something that is "secret".*
- *Information between two persons.*
- *Information not discussed.*
- *Keep information to specific people.*
- *To be well hidden.*

Carers said:

- *There are some things we may not want other Somali to know*
- *Only concerns particular people involved, no-one else should know*
- *Information that is not for everybody/private*
- *Something not to tell any body else.*
- *Information between two people.*

When the service providers were asked the same question about the meaning of the word confidential, three of them mentioned the guidelines and policies, and another two mentioned patient choice. They also said:

- *Confidentiality is determined by the client, however that you only break it, if other people are at risk. I have not found the concept of confidentiality exists within Somali culture. It doesn't seem to work. However there was one woman, who did want information kept confidential from the advocate, and I have followed her wishes. There are some Somalis here, who do work according to the Western concept of confidentiality.*
- *Information should remain privileged and private between the patient and the practitioner, unless it is necessary to preserve patient safety, and if others are in immediate danger. There are clear principles, when confidentiality can be broken.*

One man mentioned that in the rehab houses, data is locked away:

- *This means that information may be restricted, in its use, in its storage, in its dissemination. Even though the residents here, live at this house, we expect that some doors will be locked. In this home, we need to ensure that the files of patients are unseen.*

There was concern about children and confidentiality, and supervision issues, where families are discussed, but with the names anonymised:

- *There are different types of confidentiality, for example, we do discuss families, but we'd never mention any names to identify them, or addresses. Especially with children, the only time, that we would interview children, is if there's been an issue.*

In cases of risk, then it was accepted that information could be shared within the team:

- *What is shared in confidence, should remain in confidence, except abuse. A social worker shares on a need to know.*
- *Protected information, divulge if necessary to police and our teams.*

All the service providers were well aware of the meaning of confidentiality, and the boundaries of its requirements:

- *Information between client and professional is held in confidence. No others should be aware of the discussion.*
- *Not imparting information inappropriately, information needs to be respected and remain within the team.*
- *Keeping things in patient file, not sharing with third party except for care.*
- *Important, sensitive, restricted use, not disseminated widely, dealt with care, it shared with the patient's consent, within the guidelines.*

4.3.iv. Meaning of the word 'private' All respondents were asked what they understood by the word 'private'. The carers replied:

- *Something not for everybody*
- *Information between two people*
- *Information should be kept in secret*
- *Personal not to share with unauthorised people, only with consented people*
- *Not concerning other people.*
- *Not open to everybody.*

Service users gave the following responses:

- *Not open to anybody*
- *It is your business only, secret.*
- *Information between two persons.*
- *Important or very important.*
- *Information should be kept in secret*
- *Information for only one person*
- *Information of your own.*

Service providers gave the following range of responses:

- *More personal form of confidentiality.*
- *Privacy is something that is private, it has nothing to do with anybody else, it is private to that person, more personal. If something is private to me, then I don't want anyone else knowing it.*
- *Material that cannot be disclosed to anyone apart from the selected person by the persons concerned.*
- *Private to the person, the individual, it may concern the immediate family.*
- *There are areas of our lives that are very private. Between Somalis of same village.*
- *Keeping things in patient file, not sharing with third party except for care.*
- *About the individual, what they wish to share, or keep to themselves. Values and beliefs, not just information.*
- *Privileged individual alone and not shared with anyone else, without permission of the individual.*
- *Depends on context.*

4.4. Cultural Ways of Understanding Mental Health

In the final part of the research questionnaire, all respondents were asked a series of open questions, in order to ascertain their frameworks of knowledge about:

- Definitions of mental health
- Beliefs about illness causation
- Coping strategies
- Knowledge about non-medical therapeutic strategies

The responses are listed, once again according to each of the three groups: service user, carer, service provider.

4.4.i. 'Mental health': meaning of the term

Service Users: Mental Health Service Users gave the following range of responses, though three people didn't answer. They said that mental health was: *an illness, a sickness in the mind, feeling unwell in your head, being mentally disabled, having a broken mind. It happens when a patient is not thinking properly. It is the disease in the mind. It feels like an extreme headache.*

Carers understanding: Carers explained that mental health was about an unstable mind, or a mind illness or a mental sickness. They said it was about mental well-being, or anything that was to do with the mental health of a person. *'It happened when the mind is stopped, and then mental problems occurred'*. One carer noted that a person with mental health problems could get better, but also they might not get better. She said her relative used his own language. *Three years and no one understood what he was saying.* One carer said: *'Mental health is very broad, it could be from depression which is very common, to more impairing illness, some short term and others more long term but all can affect your performance or existence so it's important to identify and treat accordingly.'*

Service providers: Service providers also gave a range of responses about their understanding, and some responses were concerned with the psychological meaning of mental health. Some of the simpler responses included the following:

- *A disorder or disability.*
- *Keeping a healthy mind.*
- *Psychological and emotional well-being*
- *Person who has difficulties with functioning.*
- *We all have it, whether or not, we have difficulties.*
- *Absence of illness. Able to achieve own potential.*

One person explained: *'Mental health is a state of well-being, of the psychological and emotional person, a three-dimensional well-being, including physical. My definition of mental health is for the well-being of the individual, which is difficult to achieve at all times, because of the stresses people face in life. These can lead to mental illness as opposed to mental health'*.

Another said: *'Family illness is something that still has a stigma attached to it, especially some young people that I've worked with. My understanding is that some people can suffer from a form of mental health, but can still function extremely well on a day-to-day basis, although they have an issue that they have to deal with.'*

Some service providers explained that it was like having a balance and being able to function within society, the ability to function normally (whatever that means).

Mental health was the ability to cope with life's demands, whereas an illness debilitated the client and stopped them from everyday activities, although they could be maintained using psychology. Good mental health, they said comes from a balanced lifestyle, enabling people to be as functional and productive as they choose.

4.4.ii. Beliefs about illness causation (general)

Respondents were asked what they believed triggered or caused mental ill health. The responses from service users are set out below.

Service users: theories of illness causation. Nine people mentioned drug use and abuse, the chewing of the legal drug khat. Three people mentioned not getting enough sleep (which usually goes hand in hand with khat consumption). Also mentioned are: disappointment, stress, frustration, not managing life situations, anxiety, loneliness, and not eating properly. One mentioned the bad times and trauma experienced in Somalia. There was a concern that the chewing of khat made people think over and over again about the same issues, creating more problems without finding any solutions.

Other people mentioned a biological causes, and cultural differences. Some mentioned the combination of factors that influenced a person's mental health.

Carers. Carers were asked the same questions about their theories of illness causation. Their responses are set out below. Six people mentioned chewing khat or other drug abuse, six mentioned stress, frustration, or pressure, others said lack of sleep. One said *'Not taking correct medication, some people take other drugs so that may cause their mental health problems'*. There were also mundane triggers like hardship, or unemployment, Some mentioned social or psychological causes, like family problems, or experiencing trauma, or an *'inability to manage situations'*. One person said: *'something that happened when a person was young, like sexual abuse. Some people can't handle it. Our family didn't have a history of mental illness. It just came, it surprised us.'*

Some mentioned biological theories of causation, as part of several factors:

- *Hereditary*
- *Rare family genes.*
- *Two factors cause biological problem and pressure on the patient.*
- *Social, psychological, as well as some genetic disorders related with the mind.*
- *Some are inherited genetically; others are caused by problems related with drugs, alcohol, and social problems.*

Service providers. Mental health service providers were also asked about their theories of illness causation. Their responses included a combination of factors such as biological influences, psycho-social influences, drug or alcohol abuse, and life triggers. They mentioned things like biological factors, genes, hereditary factors, organic illness. They also mentioned that these could be in combination with a variety of factors including poverty, life circumstances, use of illicit substances, and low thresholds to normal stress.

Other factors that came in combination were housing, loss or bereavement of a person or object, change of environment, or having a traumatic history. They recognised that some people were reacting against their upbringing, or the experiences they'd had. Some people were consuming a mixture of substances such as drink and drugs. They said mental ill health could be caused by a chemical or hormone imbalance. Some people challenged the proposition that genetic makeup

could lead to people being unwell. Others noted the difference between those who were mentally retarded and biological causes like autism. One person considered mental ill health came from *'psychological deficiencies'*.

They said mental ill-health could also come up from depression, from having too much in the mind, from having an overload or conflict within relationships. People who were in transition from one culture to another may have excessive stress, they may experience a lack of support, or lack of purpose in life. They may come from dysfunctional families, having a bad childhood or experiencing trauma in life.

4.4.iii. Beliefs about illness causation (specific)

Mental health service users were asked what they believed caused their own ill-health. One man said it was by taking an overdose of drugs, and another said he was chewing khat, and was not eating or sleeping. One person mentioned stress, another disappointment, and one had immigration problems. Others had changes in their circumstances and environment, for example, they had housing problems, with low income and many children. One was triggered by the experiences he had in Somalia, which were very difficult. He said *'I cannot express this in words'*. Other reasons given were family problems, loneliness and culture shock.

Carers were asked what they thought caused the mental ill-health of their own relatives. One replied about post-war trauma from Somalia. Others gave the reason of housing problems, and family break down, personal problems and loneliness. Several spoke about taking drugs or overdosing. One person said *'it is difficult to know, because it stops you doing everything, socially and emotionally. You are isolated from your community.'*

Service providers also responded to the question about the causation of mental illness in their patients. The service providers came from a variety of practices, and their occupations have been outlined in the first section of the data report. Their responses to this question corresponded to the kind of education they had received, whether it was in health care, social care, or medicine. They noted that the Somali people had high rates of referral to the services, with multiple levels of problems. Some gave reasons of homelessness with problems of housing, and immigration status. Interpersonal conflict was given as one reason. There were also relationship problems which had broken down, and money problems. Some felt their patients reacted to their upbringing and the experiences that they had had.

Some staff gave biological suggestions for the causes of mental ill health. For example one person thought it was genetics as he had seen three brothers, with the same problem. He said they had an unsettled childhood because of the war, and this led to a lack of education and poverty. The responses were that it could have been organic illness, or a chemical imbalance.

Substance abuse and use overuse of alcohol and drugs were mentioned. They were concerned that the families tended to deny mental health problems with their relatives, and it was only when it became a public health issue that the family tried to address it with the services. Some people could not cope with the demands of their life. One service provider made the following comment, alluding to racism and mental health:

'I saw on the television when the deputy prime minister was engaged in a scuffle, if he had been from a different culture, would he have been detained under the mental health act? My patient has been diagnosed as schizophrenic, but he doesn't believe that, nor does he always take the medication'.

4.4.iv. Effects of illness on daily life (specific)

Mental health service users were asked about the kind of effects mental illness had on their daily life. They gave the following kinds of replies: *'it affected my health, my family, and stopped my development with a future'; 'it absolutely affects my daily life. I can't do anything now'*. Another said it affected his daily life badly. Others replied: *it slows me down; I feel disempowered; stress with relationships*. Another said: *'it makes me hear voices. I was disappointed my whole life and would not survive without the Somali advocacy service.'* One said it can cause family problems with the taking of drugs.

Carers were asked about the effect of their relative's mental illness on their life. They said: *'as a carer. It affects me very much, because it is a full-time responsibility to look after a sick person'*. Another said it affected them socially and economically and affected every aspect of their daily life. One person said: *'it affects my whole life in every angle, emotionally, physically, and practically.'* One person said that it excluded them from involvement in their own community, and felt that the family had to stay with the patient a lot of the time. Another was concerned, because she wanted herself and her children to be safe, and although she cared about her relative, she would not accept violence within her home.

Service providers explained the effects on mental health of their patients saying they could not make decisions, some could not eat, or live independently. Their level of functioning was impaired, they had variable sleep patterns, and they found it difficult to have a normal life or fit into society. Patients they said may become isolated and lose their self-worth. They may not have a regular routine to look after their own personal hygiene and care. They may want to work, but they fear that their benefits will go, or they may go to prison. They said patients may commit crimes as their lives became unstructured and unproductive. Communication broke down with the patient's family and friends and people became stigmatised, and got stuck in the system of trying to manage their symptoms. They had a poor quality of life.

They said some may feel hopeless with the loss of dignity, and they were at an increased risk of self harm. They were also risks about the taking of illegal drug khat. One person said: *'They go to the Somali café, which opens at 3 p.m. and take a strong khat. They go home high at midnight, and wake at 2 p.m., have lunch, and go to the café again. Women are different. Somali women do everything, the benefits, the tasks of visits. The men don't work, they become de-rolled, whereas the women can go to college and learn how to work benefits.'*

One person mentioned a woman, who had lost custody of her children, and was very unhappy about that. Another mentioned a man who had taken too many drugs and too much drink, who neglected his personal hygiene and became very paranoid, a risk to others. The service provider had to intervene to ensure that nobody else got hurt.

4.4.v. Adjustments made to cope with condition

Respondents were asked what kind of adjustments people made who had mental health conditions. The service users, explained about the strategies that they used to get better, going to the community centres and socialising. One said he aimed to sleep early, eat well and did his own cooking, whereas others found it very difficult to make adjustments to their daily life. Others said that they took medication in order to cope with their conditions and got help from the advocacy services. Others received help from their spouses or their parents in order to change their daily life. One was pleased that he had been helped to get his Home Office documentation, and that he followed the instructions given by NHS professionals and he tried to reduce his consumption of khat.

Carers had to make adjustments as well for their jobs, their holiday, and their family relationships. They had to give more time and care to their relatives, and also take care of their families. One said, I accept the problem is my own problem. Others commented that it reduced the time they spent with their own family, at work and socialising. They had to be full-time carers and do everything and use their spare time to deal with their relative's mental illness. One person had to leave work early in order to have time with their relative. Others had to care for their children.

Service providers were also asked what coping strategies their patients had to address the mental health problems. They said people took medicine and accepted that they had a lifetime illness. One man was concerned about the people living in his rehabilitation home. He said: *'The people in this unit, they're supplied with food, with free accommodation, and then they are given benefits. They used their benefits for drugs and alcohol. That is the only thing for them to do. There are not much activities here for them to do, there is nothing for them to join in, they are left idle. What else can they do? They need more therapies than anything.'*

He was concerned that benefit money was being used for drugs and alcohol, and there were not enough activities for people to join in nor therapies to support them psychologically. Some service users were willing to take their medication to prevent relapse, and attend occupational therapy sessions interacting and co-operating with others, and setting goals of their lives. Another said that the residents at the open home did try to engage in the daily activities, and develop their own life skills like cooking and shopping, or like going to the gym.

There was a concern that people identified themselves primarily as service users. Some patients did have psychological treatments, and they attended daily activities in day centres and received support from care coordinators once they went home. People who heard voices were coached so that they could learn to live with them in daily life.

4.5. Cultural Practices and Mental Health

4.5.i. Practitioners in Somalia

Mental-health users were asked what kind of practitioners there were in Somalia, who dealt with mental health problems. One person explained: *'Religious healers offer treatment in Somalia because there are no health centres'*. While another person said *'We go to mosques, where they read koran on you. There are special passages, depending what is disturbing you. We can find cure in koran. There are religious practitioners who read the koran here in Harrow. Everywhere. There are Somali imams'*.

They mentioned that people sought help from religion, from the mosque, and went to traditional or religious healers, to the Sheikh or the Sheikhad. I was told that there were no Somali practitioners in Harrow. Other people did not know what practitioners were available for treating mental health problems in Somalia. In all, 11 people mentioned that patients would use religious or traditional healers, or go to the mosque.

The carers also mentioned traditional and religious healers that were used for mental health problems in Somalia, and these included the sheikh and herbal doctors. Some said there were mental health hospitals. Others said that patients went to the mosque and recited the Koran, but they may also go to alternative or medical doctors. One person was very unhappy about alternative practice: they said *'I don't trust them any more. I took him to a Sheikh. He read the Koran over his head. They give a false hope. To read prayers over him never hurt.'* Another wanted their relative to be able to go to Friday prayers in Harrow with their befriender.

The service providers were also asked if they knew what kind of practitioners there were in Somalia for people who had mental health problems. Some had no idea, and one wondered if there were psychiatrists, or if they tied patients to a tree. One said he wondered whether there were witch doctors, or someone with authority within the community or tribe who would work with them. Another thought they would be taken to a doctor. One person thought there was somebody from the community who worked with hypnotism, and others who went to church for prayer. One person mentioned the use of priests, to address someone who was possessed by evil spirits. People thought that perhaps the family would have a greater sense of responsibility in Somalia.

There were others who knew about the religious treatments for mental health, they knew that there were no psychiatrists in Somalia. Some people went to the religious wise men (Hakim) to do a reading of the Koran, and there were others who practice Islam. One person said they went to: *'Faith healers, sheikhs, koranic readers. There is a popular person in east London. Somali women go there. They may be Indian. There is also someone in Brent, who is Bengali. They are all Muslim. There is a female therapist in Hammersmith.'*

Another said: *'Here, Somali people would not want to go to mainstream services, because of the stigma, and also they feel disempowered. They would rather consider alternatives from their own communities, going to family members, or religious practitioners. Very few people want to go with mainstream. In Harrow, they go to complementary therapies, the religious community.'* In Somalia, they said there was a lack of access to specialists, so people use religious and spiritual leaders.

4.5.ii. Alternative practitioners in Harrow

I wanted to know what other kind of practitioners there were in Harrow. Eleven of the service users mentioned the importance of using the NHS. They mentioned that there were religious practitioners and said that the advocate had advised one person to go for Friday prayers. Other people said that there were no Somali religious services in existing in Harrow. However, two people mentioned a religious person (sheikh), who attended the home and read the holy texts for the treatment of mental health problems.

The carers thought that the NHS was the most useful for the patients, although others said that religion played an important part in treating people as well. One person commented that he felt there was no effective community cohesion in Harrow. Seven carers mentioned religious aspects to treatment such as going to the mosque and talking with Elders, all reading the Koran. One said *'the mosque is very crucial to the Somali people,'* and another said that *'reciting the Koran would make people feel better'.*

The service providers were aware of the many different kinds of NHS treatment available in Harrow, including the community mental health therapists, the GP, Northwick Park Hospital, accident and emergency department, drug and alcohol services. There was also an awareness of psychiatry, psychotherapy, social workers, occupational therapists, community nurses, and community workers as well as the crisis team and the clinics at Atkins house and Honeypot Lane. There was also an awareness of the charity is, a floating support worker, church groups and day centres which could be used to support mental health patients. One person said: *'In Harrow, there are a lot of Somali associations the clients may go to for support. There are people who work with the youth offending team, to combat Islamic extremism. Community centres e.g. Bridge trust, YOT.'* Others were aware of the community development workers and interpreters.

Service providers were aware of some of the faith-based support available, through churches and prayers, and that guidance could be sought from faith and religious leaders. There was also a private psychiatry services available and people could if they want seek holistic therapies independently.

4.5.iii. Opinions about Harrow Services

Respondents were asked their opinion about mental health services in Harrow. The service users thought that there were more activities that they could do, while some said the services could be better. Four people said that the services were nice, and one that they were helpful. One person said that they were excellent, and another that they were very good and thanked them for the service they provided.

Of the carers, one person thought mental health services in Harrow were good and efficient or the best in west London and another person said it was good compared to other parts of London. Three people said it was good and one said it was excellent. However, one person wanted more support: *'We need support as carers, to help people in their own houses. Their service was excellent. They did such a good job. Since he has been in the care home, it is good. I think we carers need support, so our relatives can stay in our own homes. I didn't feel I was getting the help I needed. I feel the system only helps the people who are in their hands, not*

when people are in their own houses. That is one reason I don't want my brother to come back, he gets better help where he is, not independent in my home.

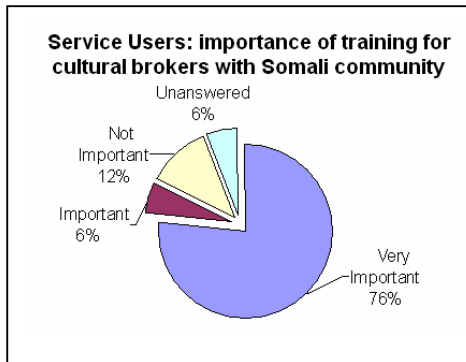
It breaks my heart that someone else is helping my brother, but he was not getting the right care and support he needed in my home. There should be outreach for patients staying in their own home. To find out what the carer needs, how to help the patient.'

The service providers also made comments saying that the service was good, and efficient, noting that Harrow was better than some places. One person felt that the client to staff ratio, in terms of cultural mix, was not representative of the population. One person said *'Harrow does their best but there is a need for more funding, accommodation needs are unmet. We need culturally appropriate services.'* *'Don't have as many rehab projects due to funding, lack of resources, small borough, 'bit of a mess'. Mind projects are good for people from different backgrounds.'*

Another said: *'I think the mental health services are great, as we have a lot of overlapping cases with them, where one parent may suffer from mental health, or there may be some concerns around children. Sometimes we make joint visits, where we explain to the child that mum or dad is suffering. We do joint working'*.

There was a concern about the local NHS: *'They are doing their best, but they are finding it hard to make the transition from the medical model to the cultural model, and a more holistic recovery model.'* Several people complained that they were not enough resources, but considering the resources that there were, they thought services were reasonable, but could be better. One person thought that the services could be improved because there was not enough access to specialist services for specific illness, and not enough adequate social housing, so patients were forced to remain in hospital. There was a comment that there were some ethnic groups with whom there was no focus on recovery, just managing risk, and the paperwork.

4.6. Importance of Training for Cultural Brokers

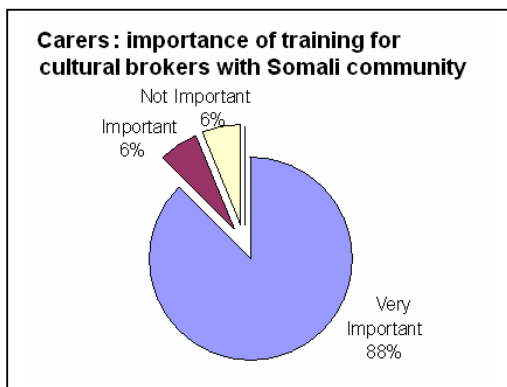


All respondents were asked whether they felt it was important to train people as cultural brokers and advocates of the Somali community. When service users were asked 76% of them said it was very important, 6% that it was important, at 12% that it was not important, and 6% did not answer the question.

One person explained that service users needed an advocate as a mediator between them and the host population: *'people from other cultures need to adapt to new culture... so need some people that can help them to do that.'* They said it would provide more help for those who needed it. One person said it was crucial that people learnt about their culture. It would help to *'build bridges and illuminate any misunderstandings'*.

They felt that cross cultural understanding was very important, so that it improved the relationship between the patient and the service provider. They also felt it was important for the advocate to be trained to have knowledge about other cultures, *'because some people need to have knowledge about the differences and similarities among cultures'*. Finally one service user explained that the *'Somali community need to know the cultural differences that exist between their home culture and their new home (western culture)'*.

Service users felt it was important to have an advocate, who could help them adapt to the host culture, and who could help to explain their culture to the professionals.



Carers were asked the same question about the importance of training cultural brokers and advocates within the community. They replied that 88% of them thought it was very important, 6% that it was important and 6% that it was not important.

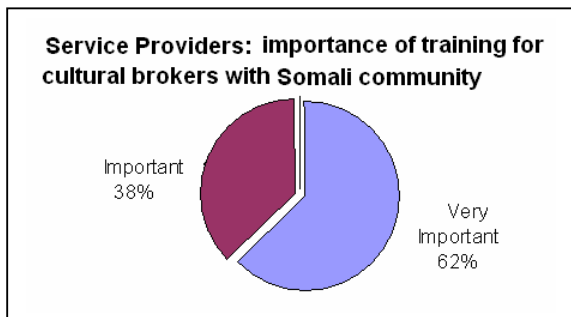
Carers gave various reasons why they thought it was important to train people as cultural brokers. They felt *'Somali needs should be covered and serviced properly.'* They wanted to help Somali people in UK gain awareness of aspects of mental health and other important issues related with life in the UK. This would *'build bridges'* and *'fill the cultural gap between western system and Somali culture in terms of mental health'*.

One person said that training was *'very important because it helps the community to understand the cultural variation existing here and back home.'* They considered that it would help people to access the services here. They also felt it was appropriate to train in having an understanding of religious and culturally appropriate services *'because not all mental health problems can be treated with medication alone'*. Carers wanted to *'bridge the social, medical and cultural gaps of the patients and service providers'*. Anyone who represented them should have the appropriate cultural background.

One person felt that training *'should be top of the agenda. 100%.'* This would ensure that practitioners did not misinterpret patients: *'the carers were aware cultures are very different and many restrictions are set by culture/religion, so it's important to understand and to find common solutions and compromises.'* The key aim was *'to overcome the cultural barriers between the concerned families and the service providers'*.

Carers felt medication alone was not enough to treat mental health problems.

Service Providers: The service providers were asked the same question about training for cultural brokers and advocates: 62% of them thought this was very important, and 38% that it was important.



They said that correct training was important, as one person said he hadn't learnt much about Somali culture from his client. They were concerned that there were high numbers of Somali people within the mental health services in Harrow, and a high number who relapsed. One explained that if the Somali people were not integrated, they would be *'left behind in terms of education'*. He felt training would increase peoples' aspirations. There was also a concern that care workers may only have a *'little knowledge of Somali culture'*. With an appropriately trained advocate, professionals would *'get a better understanding of cultural beliefs and diversity'*. This would also help to raise awareness of religious and spiritual beliefs of that society, which support well being.

Service providers were aware of the dangers of isolated communities, and considered training was important, and should incorporate supervision. Cultural brokerage was *'essential to avoid misunderstandings'* and *'to act as a bridge'*, so that staff understood about things like chewing khat and unemployment. They felt advocacy could: *'facilitate understanding between the patient and service provider, and point towards treatment'*.

However one service provider considered that it was *'important for some conditions, not for others. What we have is enough. We do need people who know how to do it.'* He also felt that advocates were needed from different cultures. One person commented that the training should go both ways: *'it is a two-way process'*. They wanted their values and work procedures explained to their Somali clients and families, and they wanted the advocate to help them understand more about Somali culture and values. They thought this would enable a better understanding of mental health practices and ways of working with professionals.

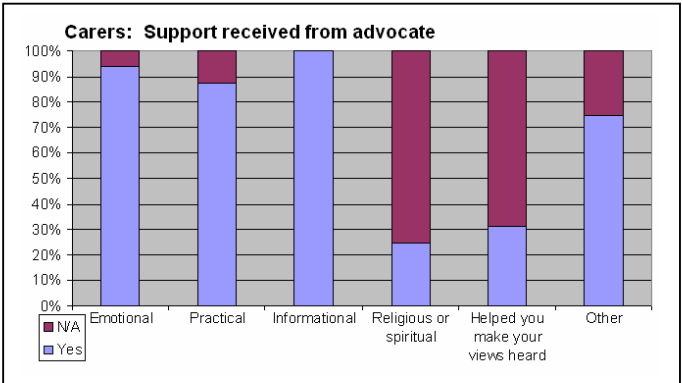
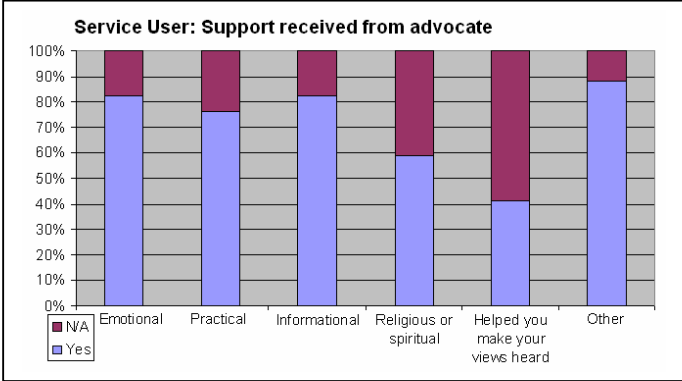
One service provider explained: *'Training in both British and Somali cultures important, (we) need to explain things like eligibility. This will help them accept how things work, so that they understand about fairness. The advocate can explain why it's fair, why it doesn't work that way'*.

Service providers felt it was important for advocates and cultural brokers to be trained *'so they learn to work professionally, observe boundaries, and work easily in an inter-agency atmosphere, and learn collaboration.'* Another person also wanted two way training, but also said that training was needed for practitioners to become more aware: *'We need to train people, so that we can become more culturally sensitive. Even though we preach equality and diversity, mainstream services are not.'* He thought it might be *'difficult to provide training on this within mainstream services'*.

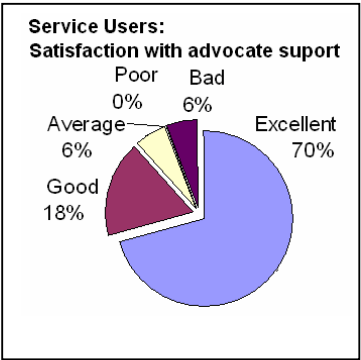
Service providers considered that it was very important to have a trained, supervised advocate. The advocate training should incorporate two-way training, for future advocates to learn about western values and procedures, about which to inform users and carers. Also it was important to train them which aspects of Somali culture it would be appropriate to explain to service providers. They felt advocates were needed from different parts of the country and from different genders.

5. Effectiveness of Somali Advocacy

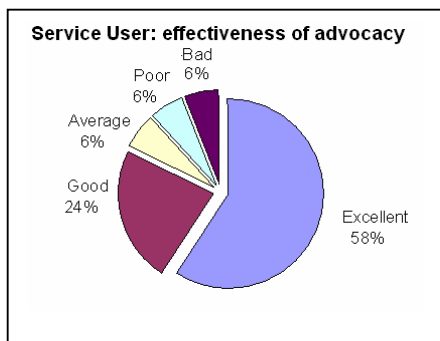
This section is written in response to the questionnaires, whereas the interviews with the advocate about his effectiveness are set out in chapter 7.



5.i. Support Received. Interviewees were asked what kind of support they received from the Somali advocate. 80% of the service users, said the support they received was both emotional and informational, and 75% said his support was practical. 58% said he also supported them from a religious or spiritual perspective. And 40% of them were helped to make their voice heard. They said that he helped build trust and gave moral support, and continuous family contacts. He also helped with educational and legal aspects for example, with one person who had a home office appeal.

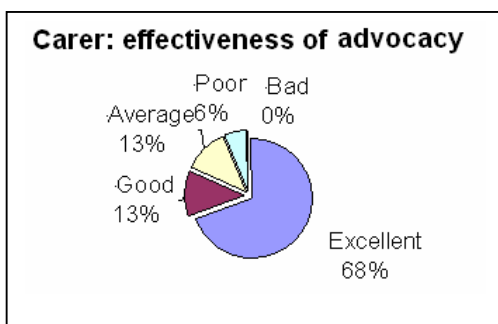


A total of 70% of service users thought the Somali advocate support was excellent, 18% thought it was good, 6% thought it average and 6% thought it bad. With regard to effectiveness, 58% of service users thought the advocates effectiveness was excellent, 24% thought it was good, 6% thought it was average, 6% poor, and 6% bad.



The advocate was not only working as an intermediary with the mental health care services, but also helped his clients in other areas. One man was very positive about the advocacy service: *'It improved my relationships and situation, as I was a very neglected person and lived about 12 years in 14-15 Kenton Road. Now as a result of Somali advocate I am going to be allocated a private (not shared) home.'* Another said *'he helped me through difficult times, even with my Home Office status.'*

From the carers' responses, 100% of them felt he gave support from an information perspective, and over 90% from an emotional perspective, 86% of them felt he gave practical support to their relative. Only 30% of them felt that he helped them make their voice heard, and 25% felt that he gave religious or spiritual support, as he explained to staff about the Muslim religion and its requirements.



When asked how satisfied they were with the advocate's support, 69% said it was excellent, 19% said it was good, 6% said it was average and 6% said it was poor. When asked about effectiveness, 68% said his advocacy was excellent, 13% said it was good, 13% said it was average and 6% said it was poor.

One person said *'He was the only one to help and explain'*. Another said *'We need more advocates for the community.'* They felt he *'really helped with family issues'*. He was *'there when needed, good contact with family'*. One was pleased and said *'he was available whenever I needed advice, general guidance and support.'* One carer felt that the advocacy was helpful for Somali people. She said: *'I spoke English already, so I knew what to do, but someone who didn't have English, it would definitely help.'*

Over 30% of the service providers felt that the advocate gave practical and information support to their client, 12% felt he gave religious or spiritual support, and over 80% felt he helped make their client's voice heard. He helped to clarify clinical procedures for the client and their family. One said: *'the residents felt more empowered when he worked with them. There was someone to listen to them. He helped with translation, part of the care plan arrangement. He created a place where mutual understanding could take place.'*

One person said he had been very helpful over a particular case that required entering a property: *'the advocate accepted my concerns over the case. As a result of the client's behaviour, with his neighbours, in order to protect the neighbourhood, I had to go in, under the mental health act, and the advocate understood that. This made things easier in the longer term, that he could appreciate my point of view on that. I had no choice. I would have had to go in with the mental health act whether the advocate agreed or not.'*

One person gave an example of the advocate's over working or wanting to take sole responsibility, where there was another paid worker to do the job. He said: *'at one meeting, a floating support worker for the client was willing to do quite a lot of work, which the advocate wanted to do himself. So we allowed the advocate to take the lead on that. I did feel that he was taking on too much for himself as one man.'*

He also gave a more positive example of support: *'The advocate most helped me with engagement with the client. I am not the same race or nationality, as the Somali people, and when they attend the mental health services, they may feel suspicious of me'. He also said 'his input improved the relationship between family members, and often meant that there were more people around to support the client.'*

However, one mental health professional explained that although the advocate accepted his concerns about the case, and did help him to explain his concerns to the family, he said that another client *'was very adamant that she did not want the advocate involved for fear of gossiping.'* He continued: *'there were things that she told me, that she did not want the advocate to know. This may have been because his wife was from the same tribe and area that the client was from. There was a fear of gossiping. This is a case for having advocates from more different parts of the country.'*

Several healthcare professionals felt that they had received no support from the advocate, and one felt that there had been a breakdown in trust, another that he was *'aggressive'*.

5.ii. Benefit from advocacy.

Service users who responded to this question all reported beneficial effects: from feeling more happy and remembering more, to having an understanding about a recovery model of mental health, and having better accommodation. Five people mentioned about coming back into the community:

- *I feel more happy with life.*
- *Mood improved. Started to remember things better.*
- *Patient is currently satisfied with the services from the advocate.*
- *Because now I live properly in a house, before I was sometimes homeless.*
- *Yes. The general public benefits as a result of improved mental health users. Service providers see us now as treatable patients.*
- *The advocacy provides emotional support, informational support, and other support so because of that the patient can recover or come back into the community.*

Carers explained the benefits too, as the advocate helped their relative begin a new life, and supported them in making better informed decisions. One person said he felt more listened to, and wouldn't have got support without the Somali advocate.

- *Because it has helped the patient to begin a new life.*
- *He took the weight off my shoulders, someone to turn to. It helped me understand more, but I do want more contact*
- *Improved mental health of the patient - benefited family and friends.*

- *We were able to make better-informed decisions as a result of his counselling/advice and assurance of someone with clout on your behalf.*
- *He helped the family cope with patient and made connection with mental health services, explained the procedure to follow.*
- *" I am going to say Mind in Harrow people well done for efforts and contribution to Harrow community as whole and particularly Somali people."*

Service providers were polarised. Some said the advocate improved contact with the family, and helped to find the patient, when he went missing. They say he helped the client's voice to be heard, and helped patients, carers and service providers see each other's perspectives:

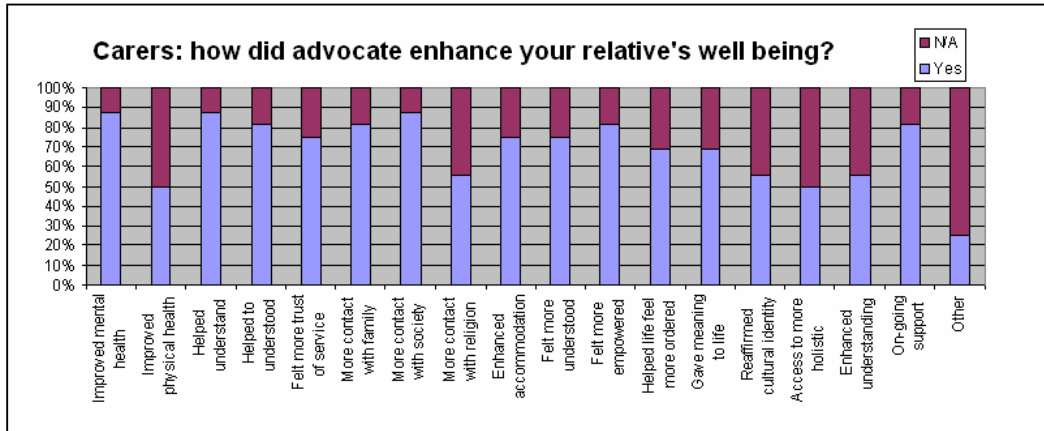
- *Helped voice client's concerns. The advocate helped us make contact with the family,*
- *More family contact for patient- relative comes to visit once a week, better understanding. Patient tells advocate of all the places he goes, so he can be found. Client has mobile so he can be contacted at any time.*
- *Understanding of each other's perspectives. Importance of medication, not chewing Kat, understanding responsibility. No response shift or change of behaviours as a result of advocacy.*

Other said there was no response shift as a result of advocacy, that his role was more important to some, but not to others. One person explained that the family was not happy with advocacy, and his presence could be detrimental to patients. Service providers wanted a collaborative rather than confrontational approach to advocacy:

- *The advocate contributes to a degree to their well being, if there is an interpreter. Some patients see his role as more valuable, for others it is not a major component.*
- *Family not happy with advocacy. Patient unaware of attempts made to help.*
- *potentially detrimental to overall well being, too quick with interventions.*
- *We need to change from the inside, and have collaboration not confrontation.*

5.iii. Enhanced Well Being.

With the service users, over 90% felt they had improved mental health, as a result of interventions by the Somali advocate. Over 60% felt they had improved physical health, and he helped them understand the drugs. The majority, over 60% felt they had more trust of service providers, understood the Western medical system better, and had more contact with their family, with their society, and with their religion. Over 60% also felt that they had enhanced accommodation as a result of the interventions. Over 50% felt the interventions gave more meaning to their life, and reaffirmed their cultural identity, and over 60% considered that they were receiving ongoing support. Only a few felt that they received access to more holistic therapies as a result of the intervention.



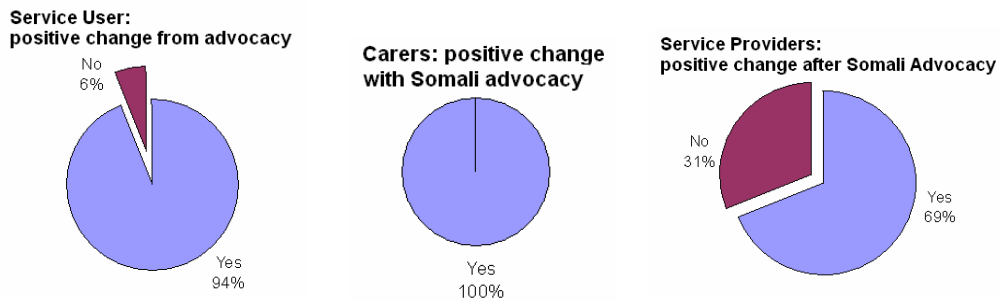
Regarding the carers, over 80% felt their relative had improved mental health. The advocate helped them understand drugs more clearly, and the Western medical system. They felt more trust of service providers and more contact with their family and with society. Just over 50% had more contact with religion. Over 60% felt that their relative now had enhanced accommodation, and felt more understood, and more empowered. The advocate’s input also helped them feel life was more ordered. Around 50% felt their relatives had access to more holistic therapies.

The figures were both positive and negative with regard to the service providers: 50% of them felt that intervention had helped the mental health of their patient, and only 25% felt the advocate had helped the patient understand more about the drugs, while a minority felt they helped the patient to understand the Western medical system. However 50% of them did feel that their patients felt more trust of the service provision. As a result of Somali advocacy intervention, over 60% felt the patient had more contact with their family, however, only 30% felt the patient had more contact with society, and 20% had more contact with religion. Over 50% thought their patient felt more understood. However, only 30% felt more empowered by the interactions with the advocate. 50% of service providers felt the advocate gave them an enhanced understanding of Somali cultural traditions, but less than 50% felt that the patient received ongoing support. One service provider said: *'The advocate helped us make contact with the family, and he helped each of us understand each other's perspectives'*.

Another service provider explained: *'The advocate was very useful with cultural brokerage, between the clients, the family, and ourselves, as mental health clinicians. His advice to the client improved their mental health, if they listened to him, and reduced their consumption of khat, and took some of the medication which we prescribed'*.

5.iv. Positive Change, or not?

Respondents were asked if any positive change occurred with the patient, as a result of Somali advocacy. Of service users 94% said that a positive change had happened, and only 6% felt that there hadn't been any change. With regards to the carers and families, all 100% felt that a positive change had occurred as a result of advocacy. With service providers, 69% felt a positive change had occurred, while 31% felt that no positive change had happened.



Several service users made the comment that advocacy had helped them become more integrated with their own community, and they had greater understanding of the western medical model. One felt that service providers now saw them as treatable, rather than ill for life. The service helped them acquire appropriate accommodation, and take on responsibilities for cleaning.

Service users made the following comments about the advocacy service:

- *It helps the patient to get better and back into the community*
- *It helps them follow instruction given by the service provider.*
- *The general public benefits as a result of improved mental health of service users. Service providers see us now as treatable patients.*
- *I feel more happy with life.*
- *Benefited from emotional support. Mood improved. Started to remember things better.*
- *I got the support (translation, integration, back into the community) I needed through this service.*
- *Somali advocacy provided different service that can help the patient to recover. The significant services include: explaining culture, explaining the western medical system (which I have no idea before Somali advocacy) and explaining about my illness.*
- *The patient can more easily get involved in his/her own duties and responsibilities within the community, if he receives and takes on the right diagnosis and advice.*
- *Council or Housing Associations, because now I live properly in a house, before I was sometimes homeless.*

The carers felt that the advocate had helped them understand more about medicine, and helped them cope with their relative, and engage more with the service providers, and make more appropriate decisions about treatment. The improved mental health of the patient helped the Somali community in particular, and helped them return to their community and begin a new life.

One carer said he wanted to recommend Somali advocacy to do more and help patients more as well. He said his brothers were getting better, so he felt more listened to, and found advocacy particularly good for patients who couldn't get support without Somalia advocacy. He wanted to thank Mind in Harrow and said "I am going to say Mind in Harrow people, well done for efforts and contribution to Harrow community as whole and particularly Somali people."

Carers explained about the positive changes which resulted from advocacy:

- *He helped the family cope with patient and made connection with mental health services, explained the procedure to follow.*
- *The patient can go back into his/her community.*
- *He took the weight off my shoulders, someone to turn to. It helped me understand more, but I do want more contact. We need to encourage him to leave his room more. It will be long-term benefit.*
- *We were able to make better-informed decisions as a result of his counselling/advice and assurance of someone with clout on your behalf.*

Once again there was a polarity of responses from the service providers, when asked the question about positive change. Some were very positive about the service, and others were negative, saying there had been no change, or the change was detrimental, and the family was not happy with the advocacy service.

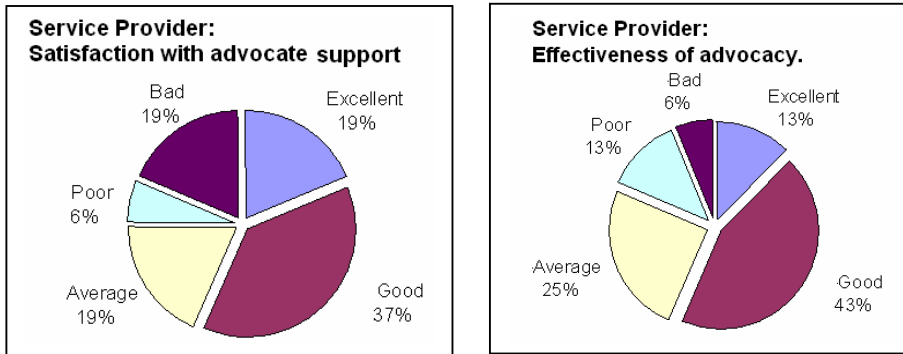
One service provider explained: *'the advocate was useful because he knew the system, and the kind of rules that we have to follow, so he could tell the families. It helped particularly with those where English was not their first language, and also if their understanding of procedures was not there.'* One person said: *'The advocate contributes to a degree to their well being, if there is an interpreter. Some patients see his role as more valuable, for others it is not a major component'*.

One professional explained that he had benefited from the contact with the advocate, though his colleagues had not: *'As a service provider, I benefited because cases became less stressful, when I was working with the advocate. The advocate may have benefited, because I was one clinician that he did get on with'*. He continued: *'If he's working within the mental health system, then he should try and get on with all the practitioners, not just a selected few of us'*. He wanted a more collaborative advocacy service, rather than a confrontational service.

Positive comments from service providers included:

- *Reintegration of patient into society. Carer understands western mental health system; need to engage, providing info for families. Service provider gained cultural sensitivity, awareness, which benefits patient.*
- *More family contact for patient- relative comes to visit once a week, better understanding. Patient tells advocate of all the places he goes, so he can be found. Client has mobile so he can be contacted at any time.*
- *Patient had depot injection on regular basis, carer brought in to assist patient and they felt supported by advocate, service provider got to know patient better.*
- *Understanding of each other's perspectives. Importance of medication, not chewing Kat, understanding responsibility. No response shift or change of behaviours as a result of advocacy.*
- *Made good teamwork with multi agency staff.*
- *He helped voice client's concerns. The advocate helped us make contact with the family, and it helps each of us understand each other's perspectives.*

5.v. Satisfaction and effectiveness. When the service providers were asked how satisfied they were with the advocate's support, 19% said his support was excellent, 37% said his support was good. 19% said his support was average, 6% said it was poor, and 19% said it was bad. When they were asked to consider the effectiveness of his advocacy, 13% said it was excellent, 43% said it was good, 25% said it was average, while 13% said it was poor, and 6% said it was bad. One said *'the advocate misrepresented the mental health service provision, minimising patient symptoms, and misrepresented factual history.'*



Others said that communication with him was *'aggressive and demanding'*. One explained *'he went outside of his role, discussed patient's illness.'* They said he had an *'overbearing attitude, he debated a cultural explanation for patient's illness, which wasn't his remit'*. One said that his satisfaction level with the advocate was *'between average and poor'*, and he explained why: *'he was overstretched as he would promise to do things for client but didn't'*. He continued *'If you don't keep your commitments to clients, then you lose your credibility.'*

One woman said she felt patronised and not heard properly by the advocate. Another professional said: *'initially, the advocate role was questionable, though later he grew into it. Now he has more awareness of the impact of mental health on people's life.'* He considered that the advocate had become *'more thoughtful in the last few months'*.

One person thought the advocate helped more people to have access to the mental health services. One considered that he was good at *'understanding CAHMS procedures. He was able to explain, in cases of domestic violence exactly why the children could not stay with their father.'* Another said he was *'helpful translating. He gave phone numbers of family to help clean room and if needed to contact if patient goes missing'*. He also helped the patient to attend meetings voluntarily, and he helped them with medication. Also he worked on their naturalisation issues with the Home Office. Another said he picked up on: *'the need within their environment, to clarify things for service providers and service users by translating, enabled more discussion and information gathering.'*

The responses from the service providers were polarised, and the wide range of their comments can be seen in the chart below. My question is: do the stakeholder organisations involved feel they need to address this polarity, or are they comfortable to accept the status quo? I have made several recommendations in the final section of this report.

Service Provider responses to: Question about how they felt during meetings with advocate		
Positive	Negative	Considered
Complements my work, bridges the gap between me and client.	Not heard properly. Advocate felt he knew all the answers, blinkered.	Advocate taking on too much during meetings. I felt that if a person takes on too much, they won't be able to give the quality in terms of the care to each of the clients.
Resident felt empowered. There was someone to listen to them. He helped with translation, part of the care plan arrangement. He created a place where mutual understanding could take place.	Threatened by advocate, who said service provider's work would 'kill a client' when actually the family was using service before advocate got involved. Both service providers and advocates need to understand procedures and scope.	At first he was more difficult. Later he eased up. It took a while for him to find his feet. He can come across as aggressive, though he is sensitive. He had strong views, but now he has mellowed and is less defensive.
Better understanding of individual, clearer objective. Listened to, good communication between client and advocate.	The advocate misrepresented the mental health service provision, minimising patient symptoms, misrepresenting factual history.	
More informed	Advocate trying to take over, felt as if he patronised her (client). Psychiatrist had to call him to order.	
Sharing of opinions, find best way forward, see both sides.	Not heard properly, irritated. I'm pro advocacy.	
Listened to, in control	Listened to, patronised	No difference.
Understood.		

It is necessary to look at the more open responses to expand on this question, and try to determine the dynamic of the relationships, and to explore solutions to any concerns. One service provider explained: *'I felt that the advocate was taking on too much for himself. I felt that if a person takes on too much, they won't be able to give the quality in terms of the care to each of the clients.'*

Regarding satisfaction with the advocacy process one service provider replied: *'With one case, yes, I was satisfied. However with the other case, I was not, because if you say you're going to do something for the client, then you have to do it. If you don't keep your commitments to clients, then you lose your credibility.'*

Interviews with service providers gave the following responses: *'The advocate was useful because he knew the system, and the kind of rules that we have to follow, so he can tell the families. It helped particularly with those where English was not their first language, and also if their understanding of procedures was not there. He can explain to the families where their expectations are unrealistic, and this helps build the connection between us a service provider and them. We don't usually use a family member as an interpreter because it isn't appropriate, we would use our own interpreter service. At least with the advocate, we know he is an external person, and whose job is to build that relationship with us.'*

One person explained how the advocate's character had changed over the two years of the project, from being somebody quite defensive and aggressive, to being calmer and more willing to understand: *'As he (the advocate) got more confident, his interventions and contribution were more appropriate. Recently he matured,*

and is more willing to collaborate, to listen, and to take advice. At first he was more difficult. Later he eased up. It took a while for him to find his feet. He can come across as aggressive, though he is sensitive. He had strong views, but now he has mellowed and is less defensive. Now he is much calmer, and he sits and tries to understand more, and to listen more. He understands the psychiatric perspective more.'

Service providers felt there was a need to unpack the requirements of the advocacy role. This was in order to explore whether advocacy was for the Somali patients alone, or as a mediator between the mental health care service providers and the patients. One man asked: *'What is his role? Does he advocate just for the patients, or for the practitioners as well? What exactly do we, as professionals, want from him? Do we have different expectations?'* This is an issue that needs to be addressed before any future advocacy project is set up, with Somali or any other ethnic group.

There was a suggestion from one service provider, about the need he felt for the advocate to work more collaboratively, rather than in a confrontational manner. He said: *'He has been very good. I can't tick excellent, because I am only talking about my own experience, because I am aware that many other workers have complained about the advocate. That's why it is good that you are collecting systematic information through the research. We need to raise awareness of the issues, and learn from them. The advocate may feel that he is challenging the power of the psychiatrists, however we feel it is better to work collaboratively, rather than confrontationally.'*

There were mixed feelings about having just one advocate to serve the community. The system at Midaye, the Somali Development Network appears to be more equitable, with up to six members of staff working as advocates, both male and female. Some clients in Harrow feared that there would be gossip if they used the advocate, and noted the problems between Somalia and Somaliland might influence support. One Harrow service provider commented: *'The advocate did help my voice to be heard, within the family dynamic. However another client's sister was very adamant that she did not want the advocate involved. There were things that she told me, that she did not want the advocate to know.... There was a fear of gossiping. It is a case of having advocates from more different parts of the country.'*

Another person mentioned the effectiveness of the advocate, saying he offered to assist the client, but didn't. If the man is overstretched, this needs to be addressed: *'with one case, the advocate said he would do certain things for the client, but he didn't, when I checked it out on the system. This is why I also feel he is overstretched, and cannot meet his own commitments'*.

Some service providers thought that the advocate was effective, and assisted with communication between them and the patient, whereas others felt he *'diminished the therapeutic relationship'*. One person thought the current system of Somali advocacy was *'almost useless for women'*. Another said that he *'quarrels with staff, misinforms patients'* and *'made the patient upset'* and *'said the wrong things to a female patient'*.

Other health care providers said there were good and bad points to the way the advocate helped patients. One said it would be useful to learn more about cultural values and *'He can explain to the families where their expectations are unrealistic, and this helps build the connection between us a service provider and them'*. He was a useful support when it came to patient's housing needs, as he provided: *'education around housing legislation, private renting and register on Locator scheme, helped people move out of borough to rent near family and friends'*

Part Three
Data Analysis from Advocate Interviews

by Josie Hinton

Chapter 6. Summary of Six Case Studies

Case 'A'				
Client's Context	Presenting Issues	What Happened	Advocate's Interventions	Outcomes
<p>A is a divorced mother in her 30's with 3 children. At the age of 12 A came to the UK with her mother and 2 siblings; A's father remained in Somalia. A's brother had mental health issues and A acted as his carer.</p>	<p>A accessed the Somali Advocacy Service. Her brother was in a secure unit at Ealing hospital and as his carer she needed support. A was struggling to cope financially. She started having hallucinations; believing that the devil was living in her home. A's children showed signs of neglect and were regularly missing school. Social Services were involved and were considering putting her children into foster care. A burnt all her children's clothes; police were called and she was charged. A was reluctant to admit she was mentally ill and had not spoken with her family about her distress.</p>	<p>The advocate found out through a friend that A was going through a difficult time. With a court case pending, A was admitted to hospital on a voluntary admission. She was diagnosed with Schizophrenia and found to have been taking drugs. Mental Health Services and Social Services had not been communicating</p>	<p>The advocate helped A, acting as a carer, to understand about the mental health system and how it works. The advocate advised and supported A in being voluntarily admitted into hospital. The advocate communicated with and coordinated the work of the different care agencies involved and encouraged effective multi-agency working. The advocate spoke with the A's family and got them to work with Social Services to organise A's children to be cared for by a friend/relative.</p>	<p>A was discharged from hospital and re-housed. A's children are waiting to join her. A is stable; she is taking her medication regularly. A accepts she has a mental illness.</p>

Case 'B'				
Client's Context	Presenting Issues	What Happened	Advocate's Interventions	Outcomes
<p>B is a 15 year old boy who came to the UK two years ago to live with his mother, step-father and younger sister. B's father lives in Somalia.</p>	<p>B started behaving erratically: being abusive towards his mother, not sleeping at night, chain smoking and drinking excessively. B was arrested by the police and charged. The family went to Social Services for support; instead of getting support for their son, they were questioned about the well-being of their 8 year old daughter. B's mother was not receiving any child benefits; the family was struggling to cope financially.</p>	<p>B was arrested by the police, a psychiatric assessment was carried out and B was taken to Northwick Park Hospital and The Priory. The assessment confirmed that he was mentally unstable. Living at home, B's behaviour deteriorated; the advocate tried to get the Child and Adolescent Mental Health Services involved but they did not follow up the case. After another psychiatric assessment at Northwick Park, there was confusion over B's records; suspected mistaken identity; under pressure from Social Services, B's mother agreed for B to be transferred to an Adolescent Mental Health Unit in East London; where B was put on medication. Social Services then transferred B to a children's home in Essex where there was no mental health care and he started shoplifting with the older boys in the home; B was charged and taken to Milton Keynes prison. Whilst in prison B attempted to commit suicide. B's mother was very depressed; she was not properly informed of her son's state or whereabouts and B's step-father was rarely at home. At a care plan review meeting at Milton Keynes prison, the professionals involved focused on the criminal aspects of B's case without mentioning his mental health. On hearing about B's mental health needs</p>	<p>The advocate initially tried to get CAMHS involved in B's case. The advocate engaged with B at an early stage to try and understand his behaviour and develop a relationship with B. The advocate explained to B's mother how she could better engage with her son and tried to communicate and work with Social Services to find out about B's whereabouts and situation. The advocate supported B's mother in attending the care plan meeting at Milton Keynes prison and requested that B's mother was involved in B's care and was made aware of any future professional meetings. B's mother spoke very little English so the advocate interpreted what was going on briefings. At the care plan meeting the advocate demanded a psychiatric assessment was carried out and that the Child and Adolescent Mental Health Services were involved in B's care. The advocate referred B's mother to a</p>	<p>B remains in Ealing Hospital under section 3. The advocate continues to support this family. This has become a high profile case with the Victoria Climbié Trust as a result of the behaviour of the care agencies involved.</p>

		<p>from the advocate, the professionals decided to hold a follow-up meeting at CAMHS; where another psychiatric assessment was carried out. On the day of the court hearing B ran away from court; 2 days later he was picked up by the police and taken back to Milton Keynes prison. However the court recognised B's mental health state, having received the psychiatric assessment from CAMHS, and transferred B to a secure unit in Ealing Hospital where he was treated and stabilized. B was given a suspended sentence with a tag on his leg. B was then discharged from hospital; but due to a lack of follow up support he was re-admitted to Ealing Hospital.</p>	<p>mental health solicitor and referred the case to the Victoria Climbié Trust. When B was initially discharged from Ealing Hospital, the advocate pressed for immediate follow-up support from CAMHS and enrolled B on a distance learning course.</p>	
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Case 'C'				
Client's Context	Presenting Issues	What Happened	Advocate's Interventions	Outcomes
<p>C is a man in his early 40's who came to the UK having lived in Holland for a number of years. Whilst living in Holland C had family difficulties; his wife left him. C's mental health deteriorated</p>	<p>Whilst living with his sister in Harrow, C started misusing Khat and becoming very abusive towards his sister; the police were called when C hit his sister. C denied he had a mental illness.</p>	<p>C was sent to Northwick Park for a psychiatric assessment and was discharged. However following the advocate's advice, C went back into hospital and received treatment. He was diagnosed with Schizophrenia. After treatment, C absconded and when the police found him he was re-admitted. Whilst in hospital C's condition stabilized and for a short period he lived alone in temporary accommodation. However during this time, C started to become unwell again and his neighbours reported him to the police. C was under the care of Atkins House Community Mental Health Team and C's care coordinator worked with the advocate to get C sectioned; C had refused to go to Atkins House for an outpatient's assessment. C was then taken to a secure unit in Park Royal Mental Health Centre.</p>	<p>The advocate was introduced to C through C's brother-in-law. The advocate worked with C's mental health care-coordinator to get him sectioned and treated in hospital. Whilst in Park Royal, the advocate got C to accept that he had a mental health problem and needed to take medication. The advocate explained to C about his legal rights and about how the mental health system works. After C was discharged, the advocate helped C to try and get his wife to the UK and become financially stable.</p>	<p>After six months C was discharged. He is regularly taking his medication and has not been re-admitted to hospital since. He wife is still living in Somalia.</p>

Case 'D'				
Client's Context	Presenting Issues	What Happened	Advocate's Interventions	Outcomes
<p>D is a man in his mid 40's who has been living in the UK for over 20 years. D has been married twice. After his second wife, an English woman, left him with their daughter, D experienced severe mental health problems. He was diagnosed with Schizophrenia, admitted to hospital and treated. After treatment he was put in a community rehab house where he has been living for twelve years.</p>	<p>When the advocate first met D he was living in the community rehab house. The advocate noticed that D was not coping; there were signs of poor hygiene and neglect. D was regularly going missing from the rehab house to chew Khat. D's Home Office papers granting him indefinite leave to remain had been lost</p>	<p>The advocate was able to find, through his connections with the community, a number of D's relatives; three brothers, two sisters and one brother-in-law. The advocate managed to speak to one of D's brothers who informed him that the family had had no involvement with D for the last 3 years.</p>	<p>The advocate referred D to a mental health solicitor. The advocate got three of D's relatives to attend the Care Plan Agreement meeting with D's consultant. The advocate got D's family involved in his care; the family started regularly visiting him in the rehab house and making sure he was properly cared for. The advocate got a letter written to the Home office, with the support of the local MP, to obtain a reference number for D's lost Home Office papers.</p>	<p>D is re-integrated with his family and they continue to support him. This has boosted his morale and self-confidence. D's family understands about D's mental health problem. D has got his papers from the Home Office.</p>

Case 'E'				
Client's Context	Presenting Issues	What Happened	Advocate's Interventions	Outcomes
<p>E was born in Somalia, the son of a diplomat, and as a child he lived with his family in the Gulf States. After finishing high school he got a scholarship to an American University; but in his second year he became ill and was admitted into a psychiatric hospital and diagnosed with Bi-Polar Disorder. When the civil war started in Somalia, E's father died; he moved to London with his mother and two siblings. Whilst living in London, E was involved in a critical incident; he had an argument with his younger sister and threatened her with a knife; as his brother tried to restrain him, he stabbed his brother</p>	<p>Whilst living in the rehab house in Harrow, E was referred to the Somali advocate by a Community Psychiatric Nurse. Initially E was very reluctant to engage with the advocate. However after a couple of visits, E explained to the advocate that he was a failed asylum seeker; he was unsure about where he was in the system. He was totally isolated; disconnected from his family and his community. E then received a letter from the Home Office threatening immediate</p>	<p>The advocate explained to E about the Home Office section and his legal rights; he also referred E to a mental health solicitor. The advocate enrolled E at the local Somali community centre. Whilst enrolling, E received a letter from the Home Office threatening immediate deportation. The advocate organised an urgent meeting with E's consultant and got a supporting letter written to the Home Office. Whilst E was making progress in the community he was recalled back into hospital by his consultant in order to change his medication. Re-calling E into hospital reminded him of what he had been through and E became very depressed. The advocate got the advice of the mental health solicitor who suggested that they get a second opinion on E's case. However the rehab house manager, on two occasions, prevented the clerk with the legal aid form entering the rehab house; thus preventing a second opinion being obtained. As a result the mental health solicitor decided to get an injunction from the court; the solicitor then sent a letter to the rehab house manager with a copy of the injunction and an</p>	<p>The advocate spoke with E in his mother-tongue language, developing a trusting relationship and giving E hope. The advocate explained to E about the Home Office section and his legal rights; he also referred E to a mental health solicitor. The advocate took E to the local Somali community centre where E could enroll on a computer course. He advocated at professional meetings for E to be engaged in social programmes. The advocate organised an urgent multi-agency meeting with the professionals involved in E's care and got a supporting letter written to the Home Office. He informed the consultant of the political and social situation in Somalia and the impact this would have on E's mental health state if he were deported. The advocate got the advice of a mental health solicitor.</p>	<p>E was granted leave to remain in this country seven weeks after the letter was written to the Home Office. He is now receiving Income Support and is looking to go to university next year. E is living independently in a private flat and taking his medication. He is living near his mother; who he now sees regularly. He has re-integrated with his family. He is still under Home Office Section but a mental health tribunal is planned for appeal.</p>

<p>in the head. The police were called and E was charged. E was put in jail where his mental health deteriorated. He was re-diagnosed with Schizophrenia. The court ruled that E should be transferred to a forensic hospital in West London under Home Office section 37/41. E was discharged from the forensic hospital to a rehab house in Harrow, remaining under the Home Office section.</p>	<p>deportation. This meant that he was no longer entitled to social care under section 117.</p>	<p>invoice from the clerk. The rehab house manager back down and allowed a second opinion to be obtained. At the same time the solicitor also requested a copy of the patient's file from the consultant. After a CPA meeting a few weeks later, the consultant decided not to proceed with re-calling E to hospital or changing his medication. The consultant realised that E was now going to college three days a week, his finances were under control and his mental health had dramatically improved.</p>		
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Case 'F'				
Client's Context	Presenting Issues	What Happened	Advocate's Interventions	Outcomes
<p>F is a man in his early 40's who has been living in the UK for the past 15 years. He graduated in India; but when he returned back to Somalia he started experiencing mental health problems. As soon as he came to the UK he was in and out of mental health institutions; diagnosed with Schizophrenia. F lived with his family in Harrow but he did not have much contact with them or speak to them about his illness.</p>	<p>F's consultant at Northwick Park Hospital believed that chewing Khat had induced his mental health problem; he felt that unless F stopped chewing Khat he would not recover. The advocate; who came to know F through his family and working in the community; believed that chewing Khat exacerbated F's symptoms but was not the cause of his mental health state. F had applied to the Home Office for indefinite leave to remain in this country; however he had filled out the form incorrectly due to his illness; when the Home Office came to make their decision, they realised the discrepancies in his application and cut off all of F's financial support. F became destitute; he could not chew Khat, his mental health deteriorated and F admitted himself to Park Royal Mental Health Centre. F refused to see his family and started being physically abusive to the nurses. F was sectioned and kept in hospital.</p>	<p>After six months of being in a secure unit, Park Royal Mental Health Centre said they could no longer keep F; he was not entitled to social care under section 117 due to his immigration status. At this point, F's care coordinator referred F to the Somali Advocacy Service for assistance with F's immigration status. The advocate suggested that if F could no longer be supported in hospital, he was sent to a community rehab house.</p>	<p>The advocate engaged with F through F's cousin in Park Royal. In order to help with F's immigration case, the advocate asked the care coordinator to give him a copy of all F's documents and asked for the support of the local MP. The advocate realised that the previous letter that had been sent to the Home Office by the consultant was not supportive; due to the consultant's beliefs about the causes of F's mental health state. So the advocate spoke with the consultant and explained how F's problems were not solely due to him chewing Khat; and how being an asylum seeker he was not entitled to social care under section 117. Another letter was sent to the Home Office and within 6 weeks F was granted indefinite leave to remain.</p>	<p>After F was given indefinite leave to remain, his mental health state improved dramatically. F was discharged from hospital and sent to a community rehab house. He re-engaged with his family; they started supporting him. F's benefits were restored. He is now living with his family.</p>

7. Thematic Analysis of Advocate's Perspectives

This section was written by Josie Hinton, as a thematic analysis of her interviews with the advocate, Abdi Gure. It covers the following topics:

- 7.1. Context: clients' personal circumstances
- 7.2. Engagement with care agencies
- 7.3. Advocate's attitudes and outlook
- 7.4. Advocate's role as 'cultural broker'
- 7.5. Approaches employed
- 7.6. Advocate's dilemmas
- 7.7. Achievements

7.1 Context: the client's personal circumstances

A number of different themes emerged regarding the circumstances of the clients' lives at the point at which they accessed the Somali Advocacy Service; however common to all six case studies were isolation, disempowerment, lack of family support, and difficulty in communicating individual and family needs. The advocate described how in five out of the six case studies clients had experienced a critical incident prior to accessing the service; clients had had previous involvement with the police, social services or mental health services and were in a desperate situation. The advocate also recognised clients' reluctance to engage with services and denial of any mental health problems. Faith or spiritual healers were frequently consulted prior to or instead of any statutory service. Issues surrounding financial and housing problems were also described as being common case characteristics.

7.1.i. Isolation

Clients' isolation was perceived to be caused or influenced by a variety of factors including: no family support, the cultural perception of mental health problems and the clients' reluctance to engage with services. In five out of the six case studies, clients had become disconnected from their families; the advocate felt that this was true of 90-95% of his clients. In one case, the advocate described how when a client was reunited his family, the client's family was surprised to see the client behaving and talking 'normally.' The family had associated his mental illness with 'acting bizarrely'. They had failed to understand that the client's symptoms could be managed with medication and that recovery was possible. In another case, he described how no family support and a reluctance to engage with services had left a client totally isolated:

'...He was very reluctant, very dubious and he was very negative in terms of engaging with me...[or] even his relatives, they disconnected with him and he was totally isolated.'

In this case study, the advocate also described the client as being 'very dubious' and initially reluctant to engage with the service; this was reflected in other cases, particularly when the client did not have any legal status in this country and was therefore frightened of any contact with the British authorities.

7.1.ii. Broken family

All of the six clients came from broken families; in the cases where children were involved, mothers were coping alone with no 'father figure' present to offer financial or emotional support. In one case, the advocate described how the 'treacherous' life of the client, coupled with no secure family unit and the additional responsibility of being a carer for another family member resulted in a desperate need for intensive support:

'...I learned from them that when she (the single mother) came, her father was not accompanying the family and he never joined, he was back in Somalia unfortunately and they were missing a fatherhood figure in the house. So that's why the two siblings had problems; I believe herself had very treacherous life with the marriage and having three children as a single mother I believe and on top of that being a carer. This was a very serious issue and she needed to be helped.'

7.1.iii. Disempowered

The advocate perceived that all of the clients felt 'hopeless' and 'powerless' lacking the capacity to change their situation. He described how most clients found it hard to express their wishes and needs to health professionals and had little or no understanding of the UK 'system.' In one case, the advocate described how the client did not ask the health professionals any questions for fear of putting his life at risk:

'What I [the client] found in the beginning was he couldn't ask any single question to any of the professionals that are caring for him because he was timid, shy. Basically this young person thought that anything that he asked would maybe risk his life.'

In another case the advocate perceived that the client 'felt useless' as a result of the dramatic change in the client's 'status' and circumstances on coming to this country:

'...I think he is having the belief before that he is useless. "Before I was graduating in India, I went back to Somalia and I became useless. I became mentally ill and coming to this country, I don't have the status, I might be deported, and I don't have any money.'"

7.1.iv. Language barrier

In four out of the six cases, the clients spoke and understood very little or no English. The advocate described how this language barrier reinforced clients' vulnerability and feeling of powerlessness over their own situation and care:

'...Imagine somebody his age who has no English language, who is illiterate...which many of my clients are. So it is like a blind person, the only thing is the oral communication, unless you get someone from his mother tongue language who can explain what he wanted it will be a very serious effect for ruining his life because nobody can help.'

7.1.v. Mental health: diagnosis and cultural perception

Whilst the key criterion for accessing the Somali Advocacy Service is the experience of mental distress; the advocate explained that a surprisingly high proportion (95%) of his 32 clients had been diagnosed with Schizophrenia. He felt that this was an issue that needed to be addressed, as it seemed statistically very unlikely to be true:

'Why on earth all these people have the same diagnosis?'

He also identified that the Somali clients' cultural perception of mental illness plays a very important role in their reluctance to access mental health services. He explained how in the Somali culture there is a proverb that says: *'when someone is mentally ill, they will never recover.'* He also spoke of the common misconception that when someone is admitted to hospital because of his or her mental health diagnosis *'they will be given a lethal injection and never come back.'* The cultural understanding is that medication is of secondary importance *'because back home when somebody's mentally ill the first priority is a spiritual healer'*. The advocate described how when someone from Somalia becomes mentally ill, it is common practice for the family to immediately contact someone who can read passages from the Koran to heal them; often this spiritual support is insufficient and ineffective but because of the stigma surrounding mental illness people will wait until their situation is critical before seeking professional help. Therefore the advocate felt that a client's acceptance of the fact that he has a mental health problem is vital in terms of recovery:

'I saw somebody who has no stigma about his mental [health], who says I healed myself when I believed I was mentally ill.'

7.1.iv. Critical incident

The advocate described how clients' often experienced a 'critical incident' before accessing the advocacy service. In the six case studies, the term 'critical incident' included involvement with the police, involvement with statutory mental health services, the risk of children being taken in foster care and the risk of deportation.

In one case, he described how a client had burnt all of her children's clothes, thinking that there was an evil spirit inside her house. The police were called and she was charged and asked several times to attend a court hearing. The advocate felt that:

'...the warning letter, that if she doesn't come to court there will be serious action taken...pushed her to come and talk to me openly.'

7.2. Engagement with care agencies

The advocate found that the clients needed to engage with a wide variety of statutory and voluntary agencies in order to get their needs addressed. Whilst the advocate did give examples of constructive multi-agency working in addressing clients' needs holistically; he also described instances where there was a lack of coordination and communication between services. He described how when working with statutory services, professionals seemed to work within a 'closed system'; where there was resistance to sharing information with external agencies or with the clients' families. The advocate felt that he was often perceived by statutory agencies as being 'a troublemaker' and outside the mainstream service provision. By contrast the advocate also gave examples of where services perceived him to be a valued community resource. He also identified what he perceived to be a Eurocentric approach to care, where the cultural importance of the clients' families being involved in the clients' mental health care was not recognised.

7.2.i. Agency culture: a closed system

The advocate described what he perceived to be a statutory sector 'agency culture' of professionals working within a 'closed system;' only sharing information with each other. He described instances where statutory sector professionals did not understand his role and found it threatening; he often challenged the professionals' ways of working and the culture within which they operated.

In four out of the six case studies the advocate described how he was 'marginalized' from the mainstream mental health service provision; this was particularly reflected in what he said in one case study interview:

'I felt like a stranger, yes. I am not in the system. I am not inclusive. I am trying to elbow somebody to say, here I am, I'm with the patient, I am standing for this patient, this poor guy, to defend him, to advocate for his medication, for everything on a holistic approach.'

In another case the advocate described how he was not included in the client's rehab house progress reports despite the positive work he was doing:

'I was doing some very positive activities, enrolling him in a computer course, opening him up, he started talking with the people, the staff in the house, after engaging with me.'

In this case, the advocate felt that the client's progress was being solely attributed to the medication he was taking; despite the fact that at one point the advocate was seeing this client on a weekly basis.

Although the advocate did give examples of where he felt recognised as an interpreter and an advocate for the patient by statutory sector professionals, he also described how they often perceived him to be a 'troublemaker' when he started to challenge aspects of their care plans:

'When I expose some of the things like the care plan, or anything that is related, then they get upset. Sometimes I am challenging them and they say "you are a troublemaker"'

The advocate felt that as a bilingual advocate from a refugee background he is:

'...looked into in a way that [is] kind of discrimination, you feel that you can't touch it openly but you feel it by trying to help, as if somebody is saying why are you helping?'

7.2.ii. Lack of coordination/communication

A lack of coordination and communication, between services, professionals, clients and their families was a common issue identified by the advocate. It is recognised that confidentiality and privacy have different boundaries in the UK and Somali cultures (in the Somali culture confidentiality includes the family rather than resting solely with the individual) and that these differences might have influenced the perception of the Somali advocate. However, the advocate described how the level of communication breakdown often left the client totally isolated from his or her own community, with little chance of ever being able to recover and live independently. The advocate described how when different statutory and voluntary sector agencies were involved in a client's care, they often failed to share relevant information with

each other, the clients and the clients' families, or coordinate the support they provided.

For example, in one case study, mental health services, children's social services, the client's extended family and the advocate were all involved in the client's care. The advocate described how the different agencies that were *'supposed to be working together, were working apart.'* Social services were focusing solely on the children, seeking to put them into a foster home and ignoring the impact that this might have on the mother's mental health; mental health services were not communicating with social services about the seriousness of the effect that the fear of the children being removed was having on the mother's mental health.

In another case study, the advocate described how information about the client's mental health was not communicated between services, as a result the client ended up in a normal childcare residential home with no mental health support despite having had two psychiatric assessments and a mental health diagnosis. The advocate described how without adequate mental health support, the client's situation deteriorated rapidly; culminating in an incident leading to the client being put in prison on remand. He explained how at a meeting with the client's mother, the professionals now involved in the client's care *'were putting all their efforts into the criminal aspects without mentioning anything [about his mental health], as if he had never had a mental illness.'*

Whilst in this case, with the advocate's input, the client's need for proper psychiatric support was eventually recognised, the advocate explained how poor coordination of support services, once he was discharged from a psychiatric ward, resulted in him being re-admitted:

'...he was discharged and we said "you have to engage him now otherwise he will go back to the same situation." He stayed a month, two months, situation has started downhill. He head-butted his mother and the wall, started urinating, refusing medication. Now he's in a secure unit at Ealing Hospital, where he has been treated before'

The advocate perceived that the time constraints put on hospital staff affected their ability to coordinate proper follow-up support:

'...when someone is discharged from hospital they [the hospital staff] have no time to communicate, like enrolling on computer courses and all this, no never.'

As well as a lack of communication between services, the advocate identified communication breakdown between professionals, the client and the client's family as a common issue. Whilst the advocate pinpointed causes including: the language barrier between professionals and users and the stigma users feel to be associated with mental illness; in some cases the advocate also described what he perceived to be *'professional negligence'*; where professionals did not include the client's guardian or carer in key care plan review meetings.

Such *'professional negligence'* was highlighted in one case study in particular, involving a 15 year old boy and his mother. The advocate described how the boy's mother was not informed that he had been sent to prison and she was not invited to a key care plan review meeting:

'There was a meeting in Milton Keynes where, after I bang many time to Social Services to invite me whenever there is a meeting, and I realized from the mother that there was a meeting in Milton Keynes at 10 o'clock. Social Services [were] supposed to invite the mother as a guardian of the child, to provide her as well [with] a voucher for transport, because she's on Income Support, to attend the meeting, to take her to the meeting, to arrange an interpreter as well in order to make her understand...I took the mother, everybody left here, without taking the mother to attend the meeting.'

7.2.iii. Constructive multi-agency working

There were examples of constructive multi-agency working identified by the advocate, where professionals from different agencies worked together and appropriately responded to the client's holistic needs, triggering a positive shift in the client's situation. In two of the six case studies, constructive multi-agency work culminated in the clients being granted indefinite leave to remain in this country. In one of these cases, the advocate described how the multi-agency care team had come together to write a supportive letter to the Home Office regarding the client's immigration status:

'So there was an urgent meeting with the consultant, with all the parties involved, the social worker, the occupational therapist, all the multi agency work for his care. At that point I appealed very strongly in the meeting and they wrote a fantastic letter...It was really, really an appealing letter and we described that if he is deported, he won't survive.'

In this case the advocate also got the local MP to write a supporting letter and *'after seven weeks the Home Office made a decision to grant him a resident's status.'* The advocate went on to describe how being granted resident's status dramatically changed the client's life:

'This has opened up to help him get income support on a weekly basis of £59 and he didn't have it before. At that time he was ready to engage with a college so he enrolled to North West London College for three days, then he could apply for Disability Living Allowance, so his finance situation, his stability was really now stable and his confidence has increased.'

In another case, the advocate described how when Social Services and Mental Health Services started *'working together in a jointly and very proactive way'* with the advocate, the client's housing and childcare issues was resolved:

'...she [the client] was refusing to go back to her house because she was believing that the devil is awaiting and again she will not feel well. So I [the advocate] could communicate with the professionals, especially with the Mental Health Care Coordinator, and she was attending every meeting, realizing and understanding the situation she [the client] was in. At the end it ended up that she has been discharged from hospital and she got a new house, and her children now temporarily under the care of someone, but they are waiting to join her.'

7.2.iv. Conflicting agency responsibilities

When describing the practices of the care agencies involved in the six case studies, the advocate identified what he perceived to be conflicting agency responsibilities;

where statutory care agencies' duty to monitor and record clients' 'risk' meant that the professionals had little time or motivation to practically engage with clients' and promote their recovery.

The advocate repeatedly commented on professionals' focus on minimizing the 'risk' of clients to themselves or others. In one case, the advocate explained how he had described the level of monitoring in an inpatient unit to his client:

'...so everything here you are observed, these people who are, you know, under the glass behind you, you are sitting here in the lodge, they are watching you.'

In another case study the advocate described how the client's need for practical engagement, not just medication, was not fully recognised by the other professionals. The advocate explained that:

'My role was always to claim that he [the client] always needs practical engagement apart from the medication, that's why they [the rehab house] couldn't offer him anything'

The advocate perceived that the professionals felt that:

'...it is better to see him some times but not expect him to recover or engage him'

7.2.v. A Eurocentric approach to care

A focus on the individual rather than the family unit; the human body rather than the soul and the spirit; and the medical rather than the social or spiritual side of a person; were all included in what the advocate perceives to be the adoption of a Eurocentric approach to care by statutory care agencies:

'...the system is Euro-centric here, yes, so only believing the physical treatment, while our people believe that we are composed of body and soul; it the same, one body, one entity, you can't differentiate.'

In his work with the six clients, the advocate adopted a family-focused model of working; the family was seen by the advocate as a useful resource in terms of care-giving and providing information about the client's history and context. He reflected on this in one case in particular:

'Yes, [the family is] very essential...in many aspects and they were telling me about a lot of his [the client's] stories, they were attending the CPA meeting, they knew that, you know, where he is in the system.'

However this way of working seemed to create tension between the advocate and mental health professionals; it moves away from the traditional western model of 1:1 work and individual confidentiality. The advocate reflected on what he perceived to be the consultant's approach to the clients' families' involvement in diagnosis and treatment:

'...the consultant says, I don't care about the mother, you are my patient and I talk to you only but the family says this is my child, I know more history, listen to what I am saying, it will be helpful to have a family narrative to have more information so when you decide his fate, don't just give the label he is schizophrenic, you have many options.'

In all of the six case studies, ensuring family involvement in the client's care and understanding the family narrative was a key part of the advocate's work. In one case study he described how by not listening to the client's story the consultant had misunderstood the causes of his client's mental illness:

'His [the consultant's] perception about this young person is that his mental state is induced by excessive use of khat, not knowing he was mentally ill when he came to this country. I knew that through my connection with the community and the family that this is not the scenario.'

The advocate went on to explain that:

'...they [the mental health professionals] didn't ask that information; they were only considering him chewing excessive khat'

The work of the advocate also highlighted the importance of a holistic approach, where the client's social as well as medical needs are recognised and addressed. For one client he explained that whilst 'nothing changed medically' for the client, when he was granted status in this country by the Home Office his mental health state dramatically improved; the advocate described how the client had become 'fully fledged' and 'back to where he belongs.'

7.3 Advocate's attitudes and outlook

It is the interpreter's view that the advocate's attitudes and outlook were influenced by the organisational culture of Mind in Harrow. For example, as a voluntary sector organisation, Mind in Harrow is subject to fewer bureaucratic processes than statutory services; this might have enabled the advocate to respond more quickly to his clients' needs. In addition, Mind in Harrow, like other local Mind associations, adheres to the organisational values of National Mind; where user empowerment, perspective and choice are at the heart of the services it provides.

Themes identified

Whilst it was difficult for the advocate to articulate the 'values' that underpinned his work as they were so integral to his every-day working practice; through the process of talking about specific cases some themes emerged. The interpreter felt that these themes were underpinned by the advocate's previous work in the community; his own personal experience as a Somali refugee; his understanding of the Somali cultural values; and his status as a Somali community leader.

A key theme was the need to take a holistic approach when working with clients; focusing not just on improving their access to mental health services but also considering the involvement of the clients' families in their care and treatment. The advocate perceived this to be an important part of a client's 'recovery' because family and community support are highly valued within the Somali culture.

Another principle theme was that of the advocate wanting 'to make a difference;' determined to change his clients' situations and bring about social justice. In one case he reflected:

' This is where I get full thrust, yes, when I see this kind of injustice and inequalities about the rights of these kinds of people, vulnerable people, young boy, suicidal case.'

Whilst it was not explored in the case study interviews, the interpreter felt that underlying this determination was a love for 'his' community; clearly wanting the best for 'his' people and as a community leader feeling responsible for their welfare.

Throughout the process of talking about specific cases, there were also examples of where the advocate clearly empathised with his clients. In one case study interview, he clearly conveyed the traumatic nature of his client's experience:

'So really it's horrendous and a punishment for the families like these who have, you know, refugee's experience without any proper structure[d] support, the provision of the service you know that existing doesn't come up with any relevant service that could alleviate the pain and they suffering, they have got it...this kind of people, they die in the middle [services]'

7.4. Advocate's role as a 'cultural broker'

The advocate's role as a cultural broker seemed to underpin and influence the practical approaches the advocate used to deal with his client's needs; these practical approaches will further be explored in the next section.

The advocate's role as a 'cultural broker' was identified in the case study interviews in the following ways: in assisting clients to communicate their distress and mental health needs; in explaining to clients the Western medical mental health model; in explaining to professionals' clients' specific cultural context; and in working with and engaging clients in a culturally appropriate way.

The advocate explained how many of his clients could not speak English and 'even those that [could] speak English, they become helpless.' As a result, the advocate spoke of how he often communicated with professionals on behalf of his clients:

'Most of the time I do the communication [with the professionals]. He [the client] doesn't feel [like] talking unless sometimes they switch to him'

The advocate felt that being able to speak his clients' mother tongue enabled him to accurately represent their needs; it allowed him to get a deeper understanding of the client's situation and family history. In one case the advocate highlighted the importance of understanding the family narrative; he explained how he had informed the client's consultant of the client's history of mental illness:

'I said do you know that this young person, when he came first to this country he was mentally ill? Two years he was kept back home during the civil war in a very difficult situation while he was mentally ill? No. So this information I gave him [the consultant] and he spoke with the [the client's] doctor immediately.'

This information was crucial in terms of getting the client the appropriate treatment; as it changed the doctor's perception of the cause of the client's mental illness.

The advocate also described how the bi-lingual nature of his advocacy increased the clients' confidence in expressing their needs and wishes:

'...it sets a kind of confidence [for the client], that they [the client] can explain what they wanted [to the advocate], that they understood the message very clearly, and they understood when the problem comes.'

The six case studies illustrated that, underpinning the advocate's work with his clients, was an understanding of how to engage with his clients in the context of their culture, in a way that they understand. The advocate reflected on the importance of this:

'...you have to communicate in a way that they understand, so they can relate, so people take it... [it is] the perspective and context we are talking about'

This understanding was illustrated in the advocate's work with the clients' families and in his outreach work. For example, he explained how, in the context of the Somali culture, it was appropriate to have face-face meetings with his clients:

'...the problem with many of the Somali patients is I have to sit down and see [them] physically, by phone, they will never believe that something can be sorted out.'

The advocate went on to explain:

'So I'm on Outreach mission all the time, to sit down, talking physically, explain, sort out things together, and then move on.'

The interpreter notes that such a heavy reliance on oral communication and face-to-face meetings presents a sharp contrast to western culture, which relies on the written word and technology as the main modes of communication; these are the methods used by health services and professionals to arrange appointments and engage with patients.

The advocate described how he used his dual understanding of the Somali cultural context and the western model of mental health to repeatedly explain to his clients and their families, in their mother tongue, how the mental health system works and the need for them to engage with services:

'because in the cultural context we believe that somebody who's mental ill will never recover, number one...So the notion of these negative things with the minds of the people coming from home [Somalia], where they never had mental health treatment or the Mental Health Act protecting this vulnerable person, its alien to them. So when I explain and I said 'this is not true,' they say 'If he's admitted or she's admitted, he will have a lethal injection, he will never come back.' I said 'No, this injection that they're taking, they're good for their health. So the brain becomes ill as any other organ in the body. So we take Paracetamol to alleviate headache or any pain, and how you feel it?' 'Yes I feel good' they respond, 'So why on earth you can't take a drug, this medication? And then you can have your holy, spiritual things, nobody will stop you. So this is the kind of communication that repeatedly I have to talk with the families in order to put them, induce them to come forward.'

In order to communicate aspects of the Somali cultural context to other health care professionals the advocate spoke of how he used specific cultural awareness training sessions:

'I have been doing several workshops with the NHS staff to explain what they [Somali patients] think about the mental illness...So this has put a notion that those who are engaging with me in the workshops, they have better confidence in receiving Somali clients.'

CPA meetings were also used by the advocate to describe a client's history and cultural context. In one case, where a letter needed to be written to the Home Office regarding a clients' immigration status, the advocate described how he had signposted the other professionals involved in the client's care to information about the post-war situation in Somalia; this meant that the professionals had a better understanding of the client's situation when writing to the Home Office:

'I was informing them [the professionals] that there was [a] report on the internet where they can get [information] about the situation in Somalia after the civil war until now. The psychiatric situation is non existent, never before and now after twenty years of civil war the situation is much worse so you can Google it I said and have this kind of report put in the letter and this is what they did, a fantastic piece of supporting [evidence in the] letter signed by the consultant'

7.5. Approaches employed

In the six case studies, the advocate identified and explored the practical approaches he used to address his clients' needs.

Five broad themes were identified to describe the approaches taken by the advocate in his work: building trust with the client; engaging with the clients' families; empowerment (facilitating independence and letting his clients' take control); coordinating services; and challenging the perceptions and behaviours of mental health professionals.

7.5.i. Building trust with the client

Listening to the client, being there in times of crisis, being honest, providing moral support and being part of the Somali community were sub themes identified within the wider theme of 'building trust with the client.'

The advocate conveyed that, in order to be an effective advocate, clients must feel able to put their trust in you:

'Yes from my experience as an advocate I felt it is a must to have the trust of the patient, of the client, that is a number one priority. Unless you have that you cannot work closely with a person or you cannot help him'

The advocate described how at the start of the 'trust building process' he maintained regular contact with his clients; making sure that they knew that he was there for them in an emergency:

'In the beginning there will be extensive visiting, extensive talk, extensive communications to try not to disconnect. What will be the worst scenario for the clients, Somalis, is to disconnect, especially when they are in need.'

The advocate felt that regular informal engagements allowed him to develop his 'relationship' with his clients and gave them an opportunity to be listened to. The advocate explained how informal engagements often took place during ward rounds. In one case study interview the advocate described how he often spoke with his clients whilst they were waiting to be seen by a doctor:

' While I'm waiting, I'm sitting with the client and I have time to talk of many things, so I utilize that time you see, many times to engage in an informal way, to make the relationship more friendly.'

The advocate expressed how being recognised as one of Somali community leaders also helped his clients feel able to confide in him:

'...being a Somali and being a member of the community and being one of the community leaders, this has given them an edge, kind of assurances that they can confide with me anything they wanted.'

7.5.ii. Engagement with the clients' families

The advocate adopted a family centered approach; as family support is an important part of the Somali culture. The advocate described how understanding the hierarchy of relationships within the client's family is an integral part of his work:

'What I do is when the person first comes into contact or refers to me, I look at the family, I look who is related to him because 90%, 95% of the clients I had were neglected by their families, this is the bottom line so I work with the families and through the community plan we have a kind of...I can't explain in detail but we have a connection. Then I try to search, sit down with them, talk to them and I ask the person first with this concept – what do you feel about you family?'

The advocate went on to talk about one case in particular, emphasizing the importance of family involvement in the context of the culture:

'One guy was telling me "I am in a rehab house, everybody is visited by relatives, they bring cigarettes, they bring gifts, nobody has come for the last two years to me" he was sad. In the context of the culture, it is very important to have family support that will boost; it is a healing itself.'

In another case study, the advocate described how the client's family had come together to organise some of the practical aspects of his day-day care and how this had dramatically changed the client's situation:

'...they will allocate one person and they will make sure that every week he comes to the [the client's] house, cleans his house, washes his clothes...and he will work with you and they did it for nine months, they become part of the rehab stuff, coming every week, cleaning his room, changing the bed sheets, washing his clothes, you know, looking [at] all the correspondence that he receives from the benefit [office], something that never happens.'

In four of the six case studies, the advocate spoke of how he used the Somali 'community plan' to engage with his clients and his clients' families. In one case the advocate explained how through the Somali community networks he knew the client's father and some of his cousins; this 'commonality' encouraged the client to constructively engage, listen and trust the advocate:

'...I engaged with him, we had a commonality. For example I knew his father by name as one of the ambassadors in Somalia and where he was based, so I knew the family. I am older than him but we had a commonality to talk about...I took him to a Somalian restaurant, we had common people and his cousins also I knew who are in Harrow...since he lost the attachment of the family, I think I represented somebody who is caring and supporting him, to whom he can trust.'

The advocate described how he encouraged and supported the clients' families to be actively involved in the clients' care and support plans by relating it to Somali cultural values:

'...because the approach I'm making is something that's related to their culture, and the notion I'm putting in front of them, it looks like they're guilty, has a guilty verdict, yes, by not supporting [the client]. Because the understanding of the Somali people for example, the culture is this is a lifetime support if he or she is mad or mentally ill, so you cannot ignore to fulfill that duty or contribute in helping this person'

7.5.iii. Empowerment

Although the advocate rarely used the term 'empowerment' in the case study interviews; through talking about specific cases, a number of activities were interpreted as being part of a wider theme or strategy of empowering the clients and facilitating independence. These activities included: encouraging and supporting the clients' to engage with their families and their community; speaking to clients in their mother tongue; and explaining to clients how the UK mental health system works.

In all six of the case studies the advocate encouraged his clients to engage with their families; empowering them to get the support they need. In one case study this meant that the client no longer had to suffer alone:

'...So being the centre focus, the young lady who put trust on me, she was really listening to me very positively, and I ask her to visit sometime, if she has time, her family and I encourage her aunt to visit [the hospital...So this has made it really the relationship much better than it was when she was suffering alone.'

In another case, the advocate described how this facilitated the client's independence:

'...so realizing that he [the client] is a community member but he has lost touch, we instigated again him engaging and encouraging him to go back to his family. I believe that this has played a vital role...giving him the confidence to engage with his community alone'

The advocate described how he felt that speaking to his clients in their mother tongue helped them overcome feelings of 'powerlessness':

'I felt that when I speak with them [the clients] in their own mother tongue language and talk about common themes, it gives them hope that they can survive, it is not the end ...they are not controlled...they are free to go wherever they want'

Educating clients about how the mental health system works allowed client's to feel more in control and understand 'what needs to be done.' In one case, the advocate explained to his client about the mental health system in order to facilitate her role as a carer for her brother:

'...while she was a carer I tried to empower her, to make her understand the mental health system; what needs to be done and what is sectioning. So I could explain to her through her own mother tongue language as well, though she speaks fluent English, how the system works.'

In three of the six case studies, the advocate spoke about his clients' denial of having any mental health problem. In these case studies, by encouraging his clients to accept the fact that they have a mental health problem and need to take medication, the advocate described how he enabled them to manage their illness. In one case the advocate recognised this as a form of empowerment:

'then he started, you know, accepting that something is wrong and that this medication helps him and if he stops he will be in trouble, so kind of empowerment because I knew the state that he was [in].'

The advocate then explained the positive outcome:

'So this has had an effect on him, when they discharged him I was asking him "are you ready to go back?" He said "Listen I learn quite a lot and now I'm attending outpatient appointments" and the most interesting thing I saw he had a coat with him [with the medication inside}...so if he's outside his house he's taking medication.'

7.5.iv. Coordinating services

As a result of the complexity of the Somali clients' needs and the critical point at which the clients accessed the Somali Advocacy Service, the advocate played an important role in initiating and coordinating the involvement of a range of agencies to address his clients' holistic needs. The advocate also felt that there was often a lack of coordination between services and that his clients frequently failed to understand 'the system' and how to access the support they needed.

In all of the six case studies, the advocate described how he had coordinated meetings and instigated multi-agency work with a range of professionals including: the local MP, mental health solicitors, Social Services representatives and Community Mental Health Team professionals. In one case the advocate described how he had been the instigated the involvement of a wide range of services

'So it was really a very complicated case in a sense that the multi-agencies [they were supposed to be working together, they were working apart, so [with] my intervention came connecting with the family, with the frontline staff of the NHS as well as the Social Services in order to attend'

The advocate went on to explain how he had encouraged mental health services and social services to work together:

...normally there is a ward round....and I suggest that the consultant should call Social Services to join the meeting so that they can be updated with what's going on and what kind of care or treatment she [the client] will have. So this has made a difference. '

7.5.v. Challenging and changing the perceptions and practices of health and social care professionals

Challenging the perceptions and practices of professionals was interpreted as an important part of the advocate's role; because at times the advocate considered that these perceptions and practices could prove unconstructive when addressing the clients' needs. In the case studies, this broad theme encompassed sub-themes including: challenging unconstructive multi-agency working; explaining to professionals the clients' family narratives; explaining to professionals the clients' cultural context; and using the knowledge and experience of other agencies to challenge the practice of statutory care agency professionals. There also seemed to be a supportive element to the advocate's role; where the advocate helped professionals to do a better job. The interpreter noted that challenging the perceptions and practices of statutory sector professionals was sometimes used by the advocate as a 'tool' to get himself heard in statutory care agencies' professional meetings.

In the case studies, the advocate gave examples of where he had challenged unconstructive multi agency working. In one case, the advocate described how this resulted in social care professionals changing their approach and practice:

'So I made the link with the family, with the Social services, and in the context of Social Services I explained that she's in the hospital and they should communicate with the Care Coordinator from the Mental Health Section in order to help and support this mother. So this has changed the tune and the approach of Social Services, because they were concentrating solely on the children.'

In another case the advocate challenged professional practice in order to get the professionals involved in the case, to recognise the need for the client to be properly assessed and treated for his mental illness:

'I bang and I said "This is ridiculous, what you are doing is absolutely wrong, this is not the right place. Number one did anyone make a psychiatric assessment of this young boy to ascertain that he is mentally ill?" No neither Harrow CAMHS nor the jail. "Why do you keep him six months, all that time? Did you inform his mother the situation that he is in?" Silent and everything was muddled really. I really try my best to ignite my full force to make sure that the direction they are going change to the proper mental health assessment, then get a treatment, then take it from there.'

Whilst it was not explored further in the case study interviews, it was identified by the interpreter that challenging professional practice was also used by the advocate, as a 'tool' to get himself heard in professional meetings. In one case study interview, the advocate referred to this directly:

'I have to make challenges on purpose to be heard'

The advocate's frustration at not being listened to and being perceived as an 'outsider' or a 'troublemaker' by statutory sector professionals often resulted, in what

the interpreter perceived to be, very confrontational meetings between the advocate and other statutory sector professionals. This was illustrated in the advocate's description of a meeting he had with one client's consultant. When the advocate told the consultant that engaging the client in art therapy was culturally inappropriate and a 'waste of time,' the following happened:

'When I said "waste of time," my God, the earthquake came, the consultant, his face shrinking, and I was, you know, "You are the troublemaker, next time make sure that I will never join this meeting," yes. So I have to struggle because I felt that I was really left behind, it was in hospital, I travelled an hour or something at least to this place, and I said "This is a waste of time, why should I come here then?" and [we continue to argue]. So this is the kind of thing that happens, and next time, when we had a CPA meeting, I remember while I was going, consultant phone me on the way and said "You are troublemaker, come and see me before the meeting," I said "No, I'm back up what you are looking for..."'

The sub-themes of explaining to professionals the clients' family narrative and cultural context has already been explored in the section: 'the advocate's role as a cultural broker,' however these sub-themes were also perceived to be valuable in terms of challenging other professionals' perspectives and practices. This was illustrated in the advocate's description of a number of instances, where his understanding of the client's cultural context and family narrative both assisted and challenged professionals' practice. These instances have been referred to in other sections.

In three of the six case studies, the advocate worked with and used the knowledge and experience of other professional agencies, for example The Victoria Climbié Trust, to challenge the professional practice of statutory health and social care agencies. In one case, where the advocate felt that the practice of the professionals involved demonstrated 'professional negligence' and where he felt that the legal rights of the client's mother had been denied, he referred the case to a mental health solicitors and the Victoria Climbié Trust:

'What I did was, I referred to a mental health solicitor for the mother, to stand with her because her legal rights about the mental health had been denied and I referred to Victoria Climbié Trust, who are in charge for advocating [for] BME [Black Minority Ethnic] [clients].'

Whilst the advocate's meetings with other statutory sector professionals were often interpreted as being confrontational, the advocate clearly perceived his role as being there to support the work of other professionals. He spoke of how he had mentioned this to his client's consultant:

'I said [to the consultant] "No I am backing up what you are looking for...I'm coming to support you, really I appreciate what you are doing to help this guy".'

Examples of where the advocate was able to support and help the work of statutory sector professionals were also given. For example, the advocate mentioned how, when working with statutory sector professionals on a case, they often relied on him to inform them of their clients' whereabouts:

'They [statutory sector professionals] were relying on me in terms of his whereabouts. What he's doing, because he was not in the radar anymore'

Furthermore, in one case study the advocate encouraged the involvement of the client's family to help the consultant get an understanding of the client's situation:

'I said can we have a meeting together, all of you, can you organise something so they'll be a CPA meeting coming up and I want you to join us at least to help and talk to the consultant.'

7.6. Advocate's dilemma: striking the balance

The advocate felt that striking the balance between effectively advocating for his clients and not coming across as too confrontational with other professionals posed a dilemma; yet it was an integral part of day-day work. The advocate explained how advocating for the clients and acting on their wishes often put him at odds with statutory sector professionals; resulting in the professionals feeling threatened or exposed and unwilling to communicate with him. However the advocate also recognised that maintaining good working relationships with statutory sector professionals was crucial; they held most of the 'power' over his clients' care and treatment plans and he often needed to work with the same professionals more than once. In conveying this dilemma, the advocate described himself as 'a diplomat':

'I have to change my hat according to the circumstances and I have to pull out sometimes when I challenge them, because they are there, we need them, yes...We have to overcome, yes, so I can't be confrontational all the time, no way, it will ruin the whole thing. Sometimes I pressure with the intention to at least make attention to me, then I can have a sideline, side-meetings to talk one-to-one after finishing the meeting, this is what I really do, to be as a diplomat'

The advocate went on to explain the nature of this dilemma:

'So it's a dilemma, it's a double edged sword, I have to talk to the patients sometimes to say 'this is the procedure', not only advocating for him, 'you have to follow this, one two, three four.' I encourage him to be engaging, yes, and in the meantime I defend him when it comes to meetings, if he doesn't have a proper care plan, if he doesn't have proper treatment, if there are side effects of medication or if he has to get with the officials, frontline staff. So I am not welcome, many, many times, yes, in the settings, when I bank on it, because when I see something is going wrong.'

The advocate also described the skills he uses to overcome these situations and how he tries to 'strike the balance':

'When I see the circumstances, I examine always, you know, the skills I use is to examine and assess during the meeting, where there are things missing, the jigsaw, and to be pushed, and I see that they are not focusing on it, they are concentrating on something else, then I try to bang already and make my noise to be heard, mess around sometimes. When the attention comes up, then I pull back and I say 'let's do it.'

7.7 Achievements

For the clients discussed during the case study interviews, the advocate's use of the cultural brokerage model of advocacy and his holistic approach in addressing his client's needs were reflected in his description of a range of achievements

The advocate described how some clients had come to accept that they have a mental health problem and they are now able to manage their condition. In one case, the advocate described how this acceptance had been part of the client's 'healing': *'Now she's very empowered, she takes her medication regularly, she understands that she has got a mental illness, was quite healing itself.'*

The advocate supported clients in attending professional meetings and challenged professional practice where necessary in order to get his clients the appropriate psychiatric support. In one case, the advocate managed to get a young boy, who had been labeled a criminal and put in prison for 8 months, the mental health support he needed:

'So from criminal offences, we succeeded to turn [the situation] the way we wanted, to get him mental health support under the care of a hospital, to be treated, and he becomes stable, and he was given a suspended sentence with a tag on his leg, curfew, to stay at home.'

In another case, challenging the consultant's decision about recalling a client to hospital resulted in the client making good progress at college and going on to lead an independent life:

'He was getting self medication...and he is going next year to university so he has moved to an independent flat...near to his mother where he can visit regularly...he is no more danger to himself or to the community.'

The advocate played a crucial role in re-uniting all of his clients' with their families. The advocate reflected on the difference family support had made to one of his clients: *'At one stage he [the client] was telling me that I feel envy with the other room mates when the relative come and they bring gifts and cigarettes...yes but now the family has taken an active role and really, really I mean they stop in the rehab house...and there was really reintegration with the family which really has, you know, boosted his morale'*

In two of the case studies, a change in the clients' immigration statuses resulted in rapid improvements in the clients' mental health. In one of the cases, the advocate described this dramatic change:

' We took the letter to the MP and then again in six weeks time indefinite leave to remain here has been granted too...after he get his status from the Home Office, within two months time his mental health status has changed. They are sending him from Northwick Park Hospital to the rehab house; they released him from the section.'

With the support of the advocate this client has now re-integrated with his family and his benefits have been restored. The advocate spoke of him now being a 'very talkative' and 'sociable' person living a 'normal' and independent life.

8. Key Points and Recommendations

This chapter presents information in the following way:

- Each page is divided into two parts: setting out the key points and recommendations in columns side by side.

The first part sets out the key issues arising from:

A) points that relate to the process of conducting the research, while the second part

B) key issues that arose from an analysis of the results of the research.
This chapter was worked on by both researchers: Natalie Tobert and Josie Hinton.

The final recommendations for the project are set out in chapter 9.

A. Research Process Issues

Research process issues include:

- bias, regarding the selection of interviewees, gender ratio of respondents, and clan.

There were also issues over:

- timing constraints over workload, and confusion as to whether the project was research or an evaluation.

There were concerns over data:

- consistency of names,
- anonymity,
- handing over of client lists for research.

Key Issues	Recommendations
8.1. Bias	
i. Selection of Interviewees	
<ul style="list-style-type: none"> • The advocate played a strong role in selecting patients, carers, and service providers to interview 	<ul style="list-style-type: none"> • Researchers need to take advice from advocates, but should not be coerced into making decisions. They need to develop trust with advocates, and line managers need to ensure that advocates trust their own compatriots. • Future projects should ensure that appropriate respondent lists and phone numbers, are not in the hands of one person alone. This is particularly important in cases where new migrants do not have much English, and are unable to make contact directly with the research team.
<ul style="list-style-type: none"> • Advocate was in the room when some interviews took place 	<ul style="list-style-type: none"> • Ensure advocate is not in the room at any time, when an interview takes place
ii. Gender Ratio of respondents	
<ul style="list-style-type: none"> • There was an under-representation of female service users, carers, translators, and service providers. 	<ul style="list-style-type: none"> • Ensure an equal number of female respondents and translators are selected for future projects

Key Issues	Recommendations
8.2. Time constraints	
i. Research or Evaluation	
<ul style="list-style-type: none"> The project had four different managers from 2007 – 2010 Steering group meetings were very sparse later during the project 	<ul style="list-style-type: none"> External Steering Group members should be invited to meet regularly, at least quarterly Managers should ensure that the Steering group is hands-on
<ul style="list-style-type: none"> There was some confusion in the first year of the project, as to whether 'research' was required (and lengthy submissions for ethical consent) or whether the project was an 'evaluation', which didn't require submission to an Ethics Committee. 	<ul style="list-style-type: none"> All stakeholders should be clear at the start of any project, about whether research is required, or an evaluation of effectiveness.
ii. Researcher work load	
<ul style="list-style-type: none"> It proved impossible to conduct the research one day a week, without support from translators, and a second researcher, on up to two days a week for 9 months. 	<ul style="list-style-type: none"> Research proposals need to factor extra time into the work plan and budget. Assessment of the project aims, feasibility and objectives should be monitored and discussed at 3 monthly intervals

Key Issues	Recommendations
8.3. Consistency over names and spelling	
<ul style="list-style-type: none"> During the recording of interviews, we noted that there were problems over the consistency of spelling of names for Somali service users and carers. Names were typed in and spelt in one way on the advocate's database, then respondents had used a different name or a different spelling, or a middle name, which was recorded when they were interviewed. 	<ul style="list-style-type: none"> Ensure the advocate in post trusts the project management with confidentiality and privacy, and understands guidelines on data protection. Ensure the advocate supplies a list of clients and their carers' names to the researcher from the inception of the project. Ensure this list of names and phone numbers is consistent and updated where necessary.
8.4. Anonymity	
<ul style="list-style-type: none"> Sometimes the advocate asked the translators to conduct interviews, without keeping adequate records, and without working with the researcher Sometimes, there was confusion with the translators, over the understanding about the need for anonymity and codes. 	<ul style="list-style-type: none"> Ensure advocates are trained to understand about research ethics and collaborative working Train and retrain staff and volunteers to ensure that the researcher's codes for anonymity are adhered to, and are never used on the interview questionnaires.

B. Research Results: Key Issues and recommendations

The research results cover the following issues: history, ethnicity and clan; service user immigration history; language barriers; gender bias; pathways and support. It also presents issues around professional boundaries, and the need to define staff roles. It addresses cultural and professional differences, and effectiveness of the service.

8.5. History, Ethnicity and Clan	
Key Issues	Recommendations
<ul style="list-style-type: none"> • Historical conflicts and prejudices can be played out in Harrow by migrant peoples from Somalia and Somaliland. • One reason people migrate, may be due to these tensions 	<ul style="list-style-type: none"> • The advocacy service needs to recognise the possibility of those conflicts and those prejudices. • The service needs to provide enough advocate workers to ensure that they offer a balanced service.
<p>The advocate was insistent that part of the questionnaire, which asked respondents to identify their clan, was not relevant and was removed.</p> <ul style="list-style-type: none"> • Two service providers commented that the advocate showed preference to people from a particular part of Somalia. • One carer noted that historical conflicts may remain between those in UK, who came from Somalia, rather than Somaliland. 	<p>It is usually significant when stakeholders want a question removed. In retrospect this question would have been useful to provide an evidence base:</p> <ul style="list-style-type: none"> • If claims about favouritism or preferential support are made, the data can be proved or disproved. • Ensure that any advocates and translators used by the project are representative from each part of a country in conflict

8.6. Language barriers	
Key Issues	Recommendations
<ul style="list-style-type: none"> • Poor English appears to be an added factor in the mental distress of migrant peoples. • Almost 50% of service users said their English was average, poor, or none. • Over 90% of carers said their English was good or excellent. 	<ul style="list-style-type: none"> • Develop a policy to ensure all new migrants are offered ESOL classes, to diminish any mental distress or barriers to access, due to lack of language. • Translate basic information about accessing the UK healthcare system into Somali

8.7. Immigration history	
Key Issues	Recommendations
The advocate played a key role in changing clients' immigration status and its subsequent positive effect on their mental well-being	We need to raise awareness on the impact of the asylum process on mental well being
The advocate was concerned and felt service providers were poorly aware of issues around being an asylum seeker and accessing services	Discuss ways to increase mental health service provision and support for new migrants and asylum seeking communities so they can access services
The majority of service providers and the advocate recognise the importance of hearing the service user's personal and family narrative, and their historical background.	Hearing personal narrative has been an essential part of the advocate's work and service providers' remit. The good practice of service providers exploring client history and narrative needs to be continued, in order to diagnose and treat people appropriately.

8.8. Gender Bias	
Key Issues	Recommendations
There were two thirds male respondents to the questionnaire compared to one third female	Ensure an equal number of female respondents and translators are selected for future projects
More men than women accessed the Somali advocacy service run by Mind in Harrow	Explore why fewer women than men used the advocacy service. Some reasons why there should be female advocates are set out below
<ul style="list-style-type: none"> Female issues: there seemed to be a lack of recognition or provision for dealing with issues women may not want to discuss in front of a male advocate: e.g. FGM, rape, domestic violence, forced marriage, repression within marriage <ul style="list-style-type: none"> Less than half service users said it was important to have a female advocate Just over half of carers felt it was important to have a female advocate 	<p>The majority of service providers 94%, said that it was important to have female advocates.</p> <p>Service providers' responses suggest they felt there was discrimination towards female patients, and emphasise the need for female Somali advocates to support women who need to use their services in Harrow.</p> <p>We need to develop a strategy to train and recruit female advocates</p>
<ul style="list-style-type: none"> The advocate was said to intervene in an unhelpful manner with certain female patients, so that service providers were not able to hear the patient's own story. 	Appoint female advocates, in order to support more Somali women who access the service

8.9. Cultural Differences	
Key Issues	Recommendations
There are different models for understanding and interpreting mental distress and different beliefs about illness causation, among people from different cultures	The services need to offer cultural competency training in models of health and theories of illness causation, for medical and allied health care professionals, advocates, and social workers.
There were different notions of confidentiality and privacy, which resulted in tensions between Somali advocate and mental health professionals	Two-way training needs to be set up, for advocate(s) and professionals, to help them in understanding each other's models of practice
The practice of faith and spiritual healers for mental health is recognised as of key importance.	More collaboration with the practice of faith and spiritual healers, and more focus groups, in order to link them with mental health services.
There is still stigma around mental health in the Somali community	We need to undertake more community engagement (through future advocates) and with Community and Religious Leaders in order to address stigma and discrimination
Diagnoses: the advocate observed that the majority (95%) of his Somali clients were diagnosed with Schizophrenia	Further research needs to be conducted into the advocate's observations that the majority of Somali clients were diagnosed with Schizophrenia
Somali people wanted the importance of family re-integration with users and providers to be recognised	Develop professional ways of working with the family as well as the individual client
We need to recognise the adjustments that carers have to make when a relative is experiencing mental distress	There is a need for the Somali Carers Forum at Mind in Harrow to continue as an example of good practice
Half of the service providers felt they understood more about Somali culture Some professional staff felt that they had learnt little knowledge about the Somali culture from the advocate	More professional training is required around cultural issues and concerns when working with Somali patients (GP trainings, NHS staff training) Somali advocates need to be informed about the importance of discussing cultural values with staff

8.10. Service User Triggers	
Key Issues	Recommendations
Problems that affect clients include social and environmental factors, which trigger mental distress: housing, broken family, migration, loss, loss of status, loss of employment, changing gender roles (power imbalance), financial problems, isolation, and immigration status.	There needs to be an improved knowledge about housing options for service users, both within the healthcare system and when discharged from services.
The advocate co-ordinated a wide range of services on behalf of Somali users and carers	This broad brush approach with services needs to be maintained and any new recruitments should be trained in this holistic way of working
There did not appear to be enough collaboration between the multi agencies that patients require for their holistic well being.	Improved co-ordination and collaboration needs to be developed and clearly maintained between all service providers. The role for a person with responsibility for multi-agency co-ordination needs to be defined, funded and appointed.
There appears to be a lack of communication between health care and social services	A strategy need to be developed so that service providers recognise, adopt, and audit, a model of practice that works towards addressing individuals' holistic needs (Psycho, Social, Environmental, Financial, and Political)
The advocate felt there was a lack of systematic understanding, of ways of working with Somali clients and the support services that are available to service providers	Information on good practice (in the form of a brochure?) setting out culturally appropriate care provision for the Somali community. <ul style="list-style-type: none"> • Refer to Kensington and Chelsea PCT's brochures for working with Somali people.

8.11. Service users pathways	
Key Issues	Recommendations
<p>Service users delay access to services, often waiting until they are in crisis, at a critical point</p> <p>There are still issues of stigma among some of the Somali community, who keep hidden members of their families at home.</p>	<p>We must develop preventative mental health promotion, and find ways of engaging with the Somali community earlier.</p> <p>Explore preventative work done at Midaye, Somali Development Network, funded by NHS Kensington & Chelsea, and NHS Westminster.</p>
<p>Service users have a poor knowledge about the mental health system</p> <p>Carers felt medication alone was not enough to treat mental health problems.</p>	<p>Offer information on accessing services and different treatment strategies, through focus group discussion. (see Needs Assessment reports about oral strategies to disseminate knowledge, Tobert 2008)</p>
<p>Develop a strategy so that Somali patients can build trust with service providers and social workers</p>	<p>Offer practical trips to the hospital, clinics, day-care centres, so Somali champions can actually see the system for themselves and report back to the community (ref. Midaye practices, 2010 Well Woman project)</p>
<p>The advocate felt there was a lack of advertising and publicity of the service amongst professionals</p>	<p>Invite all future advocates to attend practice meetings of different services (medical, health, and social care)</p>
<p>There appears to be a lack of continuity of support when people are discharged, and with it the risk of revolving door patients</p>	<p>Both the advocate and the service providers need to coordinate and collaborate so that they offer follow up support to clients.</p>
<p>Service users complain of a lack of occupational activities when they are in-patients</p>	<p>Liaise with OT's to take pro-active steps to provide service users with occupational activities, particularly when discharged from inpatient units.</p>

8.12. Duplication of effort	
<ul style="list-style-type: none"> Some service providers felt the advocate took on work already covered by other support staff, or made commitments, which he didn't or couldn't keep. Respondents felt the role needed to be more clearly defined, so advocate didn't perform tasks that other staff were paid to do. 	<p>Reflective supervision is needed for advocates to explore their role, and their own cultural assumptions.</p> <p>The role of the advocate needs to be clear, and each advocate needs to be trained in the role of other support staff, so each can perform their appropriate job role.</p>

8.13. Professional Boundaries	
Key Issues	Recommendations
<p>The advocate's open professional boundaries meant that he may be on call at any time of the day or night.</p> <p>Clients became dependent on one man as advocate, and expected his services to be offered immediately</p>	<p>We need to develop a more boundaried strategy for addressing advocacy:</p> <ul style="list-style-type: none"> • re. time barrier, access barrier, information on user pathways, • We need more formal structures in place to allow advocates to have a more clearly defined professional role. • Advocates must have a work-specific mobile phone.
<p>Concerns around advocate having a high profile in the Somali community:</p> <ul style="list-style-type: none"> • on the one hand he is more accessible • on the other hand, service users and carers fear gossip if they do access the service 	<p>Advocates need training and understanding in sensitivity working with clients, and in required boundaries of confidentiality and privacy, which are the concerns of Somali service users and carers, and providers</p>
<p>The use of Somali language promotes trust, but tensions are caused by bi-lingual advocacy:</p> <ul style="list-style-type: none"> - at the same time there is a risk of client's becoming reliant on just one advocate, - or, of the one advocate not giving clients the opportunity to do things for themselves 	<p>Reflective training is required for advocates in addressing client dependency/ psychological boundary issues</p>
<p>The issue about informed consent was not well understood.</p>	<p>The issue of consent amongst service users and carers, needs to be better explained, so that they understand what it means.</p>
<p>All service providers were aware of the term confidential, and of its requirements and boundaries.</p>	<p>There is a need for all future Somali advocates to be trained in the guidelines and policies required for working with service users and carers.</p>
<p>There was tension between cultures about principles of confidentiality and privacy, regarding the sharing of information</p>	<p>Address the cultural tension with principles of confidentiality and privacy about sharing information. Run focus groups to raise awareness of the issues.</p>
<p>Some Somali service users and carers were concerned about gossip.</p> <p>Comments were made by Somali people about not wanting the advocate to know details of their cases, and concern that wives were being given information.</p>	<p>Training for advocates needs to address the boundaries of confidentiality and privacy, so that it respects Somali service users and carers</p> <ul style="list-style-type: none"> • Clarify the meaning of privacy and confidentiality • Explain guidelines and policies for advocates • Address fears about gossip

8.14. Defining Staff Roles	
Key Issues	Recommendations
<p>There was not always clarity between the advocate's role, mainstream services, and the advocacy service</p>	<p>Advocacy needs to be integrated into mainstream provision and the role should be clearly defined in service users' care plans</p>
<p>There was uncertainty with both the advocate, over the role, and the medical and health care professionals' understanding of the advocate's role</p> <ul style="list-style-type: none"> • The advocate acted as a community champion, sometimes in conflict and confrontation with service providers • The service providers were expecting the advocacy service to act in collaboration, as a bridge 	<p>Managers need to decide:</p> <ul style="list-style-type: none"> • whether it is better for the advocacy service to act only as a community champion on behalf of the Somali people, • or would it be better for all, if it was a service which acted as a bridge between service users carers, and professionals, understanding concerns of each?
<p>There was a polarity of responses amongst service providers and some carers to advocate's approach and his interventions</p> <p>The advocate, as well as feeling valued as a resource by service providers, also felt he was marginalised, viewed as a trouble maker, working outside a closed system, trying to address a Eurocentric system of health care, where health care workers didn't understand his role and found him threatening.</p> <p>He considered his role was to defend the patient, and challenge staff. He felt he was discriminated against.</p> <p>Conflict developed between some service providers and the advocate for the following reasons:</p> <ul style="list-style-type: none"> • gender • aggression • overstretching • not listening to patient • role poorly defined • confrontational approach 	<p>Line managers need to define the advocates' role: whether they are a bridge, an advocate or a community champion, who defends patients.</p> <p>In order to best serve Somali users and carers, a mediation service needs to be put in place, at the start of any future project.</p> <p>If conflict arises between an advocate and service providers, there needs to be a clear mediation strategy which acknowledges the differences of understanding of all stakeholders.</p> <p>This mediation service needs to be set in place and agreed before any future service is initiated.</p> <p>In order to ensure a consistent service, structured sessions need to be in place, with health and social care professionals, and the advocates' line managers, to define the advocates' roles.</p>

8.15. Effectiveness	
Key Issues	Recommendations
<p>The majority of service users and carers felt empowered by the presence of the advocate in their meetings; however, a quarter of all service providers felt either patronised or disempowered.</p>	<p>Training, such as that offered by Action for Advocacy, would offer a quality standard framework, and result in greater consistency of practice. This would improve all advocates' interpersonal skills, and their ways of relating to medical, social and health care professionals</p>
<p>The majority (nearly three quarters of service users, and carers) considered that the advocate was excellent or good.</p> <ul style="list-style-type: none"> • Most service providers felt advocacy was excellent or good, but nearly half thought it was average, poor, or bad. Some felt advocate was aggressive at first, but had mellowed 	<p>The polarity of experiences expressed by service providers need to be addressed.</p> <ul style="list-style-type: none"> • Advocates need to be trained, according to quality standards so that the service levels can be improved across the board
<ul style="list-style-type: none"> • The Somali advocate enhanced well being for the majority of service users and carers. • Users and carers trusted the service providers more. 	<p>This was good practice, as a cultural broker, and needs to be continued</p>

8.15. Topics for training	
<p>There were various topics which need addressing for service providers:</p> <ul style="list-style-type: none"> • diagnosis of schizophrenia, • collaboration and communication between services, • role of advocates and how they might be supportive 	<p>Training topics for service providers</p> <ul style="list-style-type: none"> • Cultural values: gender, faith, and extended family • Confidentiality and privacy • Cultural practices: Khat FGM • Cultural behaviour (what is pathologised, and what is not)
<p>Service providers considered that it was very important to have a trained, supervised advocate. The advocate training should incorporate two-way training, for future advocates to learn about western values and procedures, about which to inform users and carers. Also it was important to train them in which aspects of Somali culture it would be appropriate to explain to service providers.</p> <p>Providers felt advocates were needed from different parts of the country and from different genders.</p>	<p>Topics for advocacy training include:</p> <ul style="list-style-type: none"> • Observing professional boundaries • Ways of working in a professional manner • Ways of working in a collaborative manner • Negotiation skills • Concepts of privacy and confidentiality (Somali and Western) • Gender issues

Chapter 9. Final Recommendations

9. Final Recommendations

The following recommendations are set out, with findings that significantly expand on the focus set out four years earlier, in the original proposal (Appendix A). These recommendations are presented in order to maximise benefit for the well being of Somali people as a whole. More detailed responses can be found in the section above (chapter 8) in the charts on key issues and recommendations.

The questionnaire results in Part 2 of this report, provided evidence of the polarity of positive and negative responses to interventions by the advocacy service. This polarisation and conflict was also present in the advocate's perception of his own practices and those of service providers, which Josie Hinton outlined in Part 3.

This project illustrated that the advocacy service did improve Somali users' access to mental health services. The model of advocacy which involved working with families was perceived to be beneficial, both by the Somali community, and by mental health professionals. However any future project needs to consider different collaborative models of engagement, which result in negotiated interaction between advocacy services, medical, health and social care professionals.

The recommendations set out below have attempted to grasp the polarisation and conflict, between the advocacy service and service providers, evident in this report. The recommendations offer practical steps to move forwards, to modify behaviour and enhance skills, using transferable models, with the practice of advocacy for new migrants, refugees and asylum seekers.

Recommendations address the following themes

- 9.1 Historical Tensions
- 9.2 Gender Issues
- 9.3 Pathways to Access Mental Health Care
- 9.4. Within Mental Health Care: Effective multi-agency working.
- 9.5 Within Mental Health Care: Confidentiality & Communication
- 9.6. The Role of Advocacy
 - Beneficial aspects
 - Polarities and Conflict
 - Engagement
- 9.7. Cultural Theories of illness
 - Frameworks of Understanding
 - Diagnoses of Schizophrenia
 - Questions of Misdiagnosis
- 9.8. Empowerment of the Somali Community

9.1. Historical Tensions

Managers of future projects, addressing the needs of new migrants, refugees and asylum seekers, need to ensure that historical conflicts from the country of origin, are not replayed in Harrow between partisan groups. If services unconsciously support selected community leaders, they may be excluding those from a different part of the country, or of a different faith.

- 9.1.i. Managers of any advocacy services need to research, acknowledge and understand conflicts and prejudices. Regional conflicts need to be grasped in the original proposals for services, and addressed

- 9.1.ii. The service needs to provide enough advocate workers to ensure that it offers a balanced service, which has representatives from each part of a country of origin in conflict.

9.2. Gender issues: one size does not fit all

In addition to the recommendations in 9.1, when working with new migrants, we need to explore the Eurocentric assumption and expectation, that one advocate is appropriate and enough for addressing the needs of the population. One size does not fit all.

- 9.2.i. In many cultures male and females are given quite different values. It is extremely important to respect cultural variations, and have advocates of both genders.

- 9.2.ii. Female advocates must be considered for all advocacy projects, so that female concerns such as mental distress due to rape, domestic violence, effects of female genital mutilation, forced marriage, honour, shame, aggression and repression, can be dealt with sensitively, by a person of the same gender.

9.3. Pathways to Access Mental Health Care

Asylum seekers and refugees may fear any form of authority. They may delay access to mental health care services, often waiting until they are desperate, or in crisis, or until they come to the attention of other services.

In order to enhance pathways to access health care, we need to develop more strategies to:

- 9.3.i. address stigma, isolation, and discrimination within the community

- 9.3.ii. acknowledge the key role of immigration and refugee status to a person's well being

- 9.3.iii. develop culturally appropriate ways of encouraging trust between new migrants and host communities

- 9.3.iv. offer ESOL classes to new migrants, to raise their English skills

- 9.3.v. use an advocate and oral communication, when service providers need to arrange a meeting with patients, as well as sending a letter.

New migrants and refugees may have religious theories of illness causation, which may exclude approaching health care professionals. To address this we need to:

- 9.3.vi. find ways of engaging with communities earlier (even in schools) and raise awareness of symptoms and enhance pathways to access care
- 9.3.vii. continue to undertake mental health promotion, and include religious leaders, in the ways communities suggested in the NHS Needs Assessment (Tobert 2008) and the Bridging Cultures, Dissolving Barriers report (Tobert 2010).

9.4. Within Mental Health Care: Effective multi-agency working.

Mind in Harrow's advocacy service used a holistic approach, which was appropriate and should be continued. There were several issues that arose, once people had accessed the mental health care services. These included multi-agency collaboration and issues around communication and confidentiality

Somali service users were faced with social and environmental issues, which triggered mental distress. These included: immigration status; loss due to migration; poor housing, loss of employment, broken families and changing gender roles (power imbalance); financial problems; over consumption of the legal drug *khat*, and isolation.

Multi-agency working can be successful. However, the current advocate described 'a breakdown in communication' between agencies, which he suggested amounted to 'professional negligence' over collaboration when working with the statutory providers.

In order to address concerns about multi-agency collaboration, the following recommendations are made:

- 9.4.i. A role for one person, with responsibility for multi-agency co-ordination and communication, needs to be defined, funded, appointed, and audited.
- 9.4.ii. Simplify the procedure of communication between agencies
- 9.4.iii. Develop improved co-ordination and collaboration between all service providers, maintain it and audit it.
- 9.4.iv. The model of practice that addresses an individual's holistic needs (medical, environmental, legal, social) must be supported and audited.
- 9.4.v. When services users are inpatients or discharged back into the community, they must be provided with appropriate occupational activities, which must be monitored.

9.5 Within Mental Health Care: Confidentiality & Communication

There were issues around communication, and a tension between cultures about the principles and boundaries of confidentiality and privacy, regarding the sharing of information and involvement of family members: these issues were highlighted by carers, advocacy service, and health care professionals. There was one key contention: families wanted to be more engaged with their relative's consultation and treatment, even when that relative refused.

The following recommendations are made:

- 9.5.i. The family centred approach the advocacy service used, should be continued (with patient consent), as it enhanced a patient's lifestyle and support
- 9.5.ii. At staff practice meetings, discuss the potential involvement of family members in the Care Plan meetings and arrangements
- 9.5.iii. Address cultural tensions concerning confidentiality and privacy about sharing information with services and patients' families. Offer training during practice meetings of both advocacy service and health care providers, about family models of therapy.

On the one hand, Somali people preferred group counselling and family involvement, with a more open approach to confidentiality, but on the other hand, they feared gossip among Somalis.

- 9.5.iv. Raise awareness and discuss at practice sessions the different perceptions of an individual consultation: 1:1 consultation (western model), and 1:1 plus family (with consent, African and Asian models)
- 9.5.v. Raise awareness of the different ways of understanding 'confidentiality', and the norm of working with families, with patient consent.
- 9.5.vi. Train all working within the advocacy service of the need to work sensitivity with clients, and within the required boundaries of confidentiality and privacy, in order to address clients' fear of gossip.
- 9.5.vii. Future research proposals must include clear protocols and policies to manage confidentiality between researchers, advocacy services, and health care providers.

Future projects must take into account the cultural context of confidentiality and privacy within different communities. However, line managers need to be aware that sometimes, leaders may retain authority over compatriots, and withhold information that would sustain capacity building at a community level. In situations where someone working within the advocacy service appears to be very private and doesn't appear to trust appropriate colleagues, to hold client names and phone numbers:

- 9.5.viii. Take steps to ensure all advocates trust project management and their colleagues, with confidentiality and privacy, and are familiar with policy guidelines on data protection.
- 9.5.ix. Discuss and define the interface between working models of the advocacy service and health care providers, in order to maximise effective practices.

9.6. The Role of Advocacy

Beneficial aspects of advocacy role: The role of bi-lingual advocate was very effective as cultural broker for Somali service users. Ensure future advocates continue the role, with timely interventions:

- 9.6.i. To act as interpreter / translator, to increase client confidence
- 9.6.ii. To engage with client's family and introduce them to the health care system, and inform staff of cultural values
- 9.6.iii. To work with the Home Office over immigration service, housing, carer's support, and any other required services
- 9.6.iv. To support patients' and carer's understanding of health care system and medication control.

Outreach work with different agencies is essential for patient well being, when clients are inpatients and outpatients, and should be a requisite.

- 9.6.v. The advocate's role in working on clients' immigration status had a positive effect on their mental well-being, and should be maintained.

Polarities and Conflict: There was a polarity, and initially some conflict, regarding the boundaries of the advocacy service. I have presented two polarities below.

Advocate's perception: The original advocate, as well as feeling valued as a resource by service providers, also felt marginalised, viewed as a trouble maker, excluded by a closed system, working within a Eurocentric system of health care, where staff didn't understand his role and found him threatening, and he felt as if he was not welcome. His role, he said was to defend the patient, and challenge '*the perceptions and behaviours of mental health professionals*'. Sometimes the advocate did not feel as if he was always treated as a professional, and as an equal.

Service Providers' perceptions: Some service providers found the original advocate difficult to work with at first. Some said he was: aggressive; confrontational; tried to do tasks of paid providers; didn't follow through with commitments; believed he could better diagnose Somali patients; undermined female patients; and supported his own people. Others found his interventions improved the quality of their relationship with client.

Comment on Engagement: Stafford Scott (Race for Health seminar, Sept 2010) suggested there are different stages of engagement between communities and service providers:

- first activism, in which staff criticised the public sector;
- the second stage, where one offered skills to one's community alone;
- third stage, where people worked together.

It is my opinion that the most sustainable form of engagement, to benefit the Somali people, would be partnership working between future advocates and health care professionals. Scott's report sets issues out clearly (see 'A Dialogue of Equals' published by the Department of Health in 2008, and the government White Paper: 'Communities in Control: Real People, Real Power' 2008).

In order to take steps towards engagement and empowerment, the following recommendations are made:

- 9.6.vi. The role of advocates must be better defined and boundaried.
- 9.6.vii. Explore ways other organisations that offer advocacy set their quality standards.

- 9.6.viii. For the benefit of Somali people and mental health practitioners, managers must establish a conflict resolution strategy to acknowledge and address disputes between advocates and service providers.
- 9.6.ix. In order to reduce conflict, advocates need to be trained in negotiation, diplomacy, and discussion skills.
- 9.6.x. Ensure there is no duplication of effort with clients' key workers or floating support workers.
- 9.6.xi. A conflict resolution and mediation team needs to be established in place before any future advocacy service is set up.

9.7. Cultural Theories of illness

A. Frameworks of Understanding. There are different models for understanding and interpreting mental distress and different beliefs about illness causation, among people from different cultures. Beliefs require an understanding of different paradigms, and to address this:

- 9.7.i. Develop training to offer cultural competency courses in the different models of health, theories of illness causation, and treatment strategies.
- 9.7.ii. Raise awareness about role of faith and religion in mental health
- 9.7.iii. Offer the course to medical and allied health care professionals, advocates, social workers, and religious leaders.
- 9.7.iv. Work with spiritual and faith leaders, who are often consulted first. Offer training to scholars and imams, in mental health awareness.
- 9.7.v. Training in frameworks of understanding needs to be made available through local authority, community care, and offered at Northwick Park Hospital Trust, and to GP's at faculty level.

B. Diagnoses of schizophrenia. The advocate observed that the majority of his clients (95%) had been diagnosed with schizophrenia, and he questioned that diagnosis. He felt consultants misinterpreted illness causation of some of his clients. He believed service providers did not understand the importance of hearing the service user's narrative and historical background. However evidence from the questionnaire suggests service providers regarded this as an essential aspect of their remit.

Questions of Misdiagnosis: There are wider issues regarding black men and the diagnosis of schizophrenia. The psychiatrist Suman Fernando explains: "*The current system of diagnosis in psychiatry, whereby complex human problems are reduced to reified entities denoting medical illnesses located in the individual "mind", is value-laden and likely to be influenced by stereotypes and images of people held in society*".

"The use of psychiatric diagnoses cross-culturally is problematic. Black British people of African-Caribbean ethnicity are overrepresented among people given the diagnosis schizophrenia/psychosis. This situation is explicable in terms of cultural misunderstanding coupled with institutional racism" (see also his article: DSM-5 and the 'Psychosis Risk Syndrome', Fernando 2010).

In order to address this mismatch in diagnosis, the following recommendations are suggested:

- 9.7.v. The advocacy service and health care providers need to develop a negotiated strategy for discussing differences of opinion, when advocates and psychiatrists believe they have different theories of illness causation, about a specific series of cases.
- 9.7.vi. It is appropriate for discussions to take place between clinician and advocate during a consultation about the patient's diagnosis; and for the concerned parties to feel comfortable in seeking explanations about the conclusions.
- 9.7.vii. Queries about diagnosis should be made during a consultation, rather than through the complaints procedure.

9.8. Empowerment of Somali Community

Empowerment is the extent to which people believe they can influence decisions that affect their lives. Community empowerment is the most effective strategy to create sustainable change. When there is one 'leader', this may result in mental health care or advocacy being available through one person alone. To address this, more community members need to be invited to participate.

Recommendations:

- 9.8.i. Invite capacity building for the Somali community as a whole.
- 9.8.ii. Build up a network of supporters, community champions, and advocates to serve users and carers
- 9.8.iii. Ensure users and carers are equally empowered
- 9.8.iv. Aim to develop trust between all stakeholders
- 9.8.v. Offer mental health promotion to the whole community, including to schools, youth groups, and religious organisations.

Dr Natalie Tobert,
Mind in Harrow, November 2010

Appendices

Appendix A Original Proposal to Kings Fund

Appendix B Questionnaire for Patients

Appendix C Letter of Consent